FOIA Number: 2018-0758-F

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Todd Summers

Subseries:

OA/ID Number: 21089

FolderID:

Folder Title:
Issues - HIV Surveillance

Stack:	Row:	Section:	Shelf:	Position:
S	66	6	3	1

HIV Case Surveillance

Debate Continues Over How States Should Track HIV Cases

The **Washington State Board of Health** is moving to draft an HIV case surveillance system that relies on the names of individuals who test positive.

The board voted 7-0 with two abstentions Oct. 14 to begin the process of adding HIV to the list of reportable communicable diseases. The board plans to review the draft rule at its Nov. 12 meeting.

Anonymous testing would still be allowed, but once a person sought treatment, his or her name would be added to the state HIV registry. AIDS cases are already recorded by name.

The vote represents a setback for advocacy groups in the state who came close earlier this year to persuading the state Legislature to pass a bill to track HIV cases by use of a unique identifier, instead of names.

The **Governor's Advisory Council on HIV/AIDS** voted 14-4 in January to recommend a surveillance system based on unique identifiers. The state House passed the bill, but the Senate let it die upon adjournment.

Led by the **Northwest AIDS Foundation**, opponents of name-based reporting tried to enlist **Gov. Gary Locke**'s support, but Locke left it up to the state Board of Health to decide.

Disappointed by the turn of events, the foundation now will begin educating clients about names reporting and informing them about the option of anonymous testing, public policy director **Steven Johnson** said.

Thirty-one states already require physicians and laboratories to report adult HIV cases to public health departments. Only two of them, Maryland and Texas, rely on unique identifiers. The rest use patient names. Texas is planning to switch to names next year.

In recent months, New York moved toward names reporting; Massachusetts and Illinois have embraced unique identifiers. California's governor recently vetoed legislation that would have created a code-based system.

Here's a rundown on where some of the remaining states stand:

Connecticut

A 15-member state task force has been meeting monthly to examine the issues and report back to the **Department of Public Health**, state AIDS director **Beth Weinstein** said.

"The task force hasn't taken any votes. No decisions have been made. No conclusions have been ruled in or out," Weinstein said.

District of Columbia

The District's **AIDS Advisory Committee** has created a five-member subcommittee to examine the options, but officials have not made any decisions, said Jean Papscott, spokeswoman for the **Department of Health**.

"It's not an easy issue for communities, because of concern about breaches of confidentiality and the idea that Big Brother is watching you," she said.

Papscott said the department is looking for guidance from the **Centers for Disease Control and Prevention** – and for money. The cash-strapped District government cannot easily afford to embark on a surveillance program that would require the hiring of additional staff.

"We just don't have the finances for it," she said.

Georgia

The state **Division of Public Health** has made no decision on whether to use names or unique identifiers in a future HIV case surveillance system, spokeswoman **Bernadette Burden** said.

Officials have been holding public forums across the state for the past two months, and fact-gathering will continue well for some time, Burden said.

It may be spring or early summer before a case surveillance system is in place.

Public health officials have gotten an earful at the forums. Almost all who spoke at a meeting Sept. 15 in Macon were against using names. They feared name reporting would scare away people from getting tested.

Among those speaking in opposition to name reporting were **Sidney Watson**, a law professor at **Mercer University** who specializes in public health law, and **Stephen Scarborough**, an attorney with **Lambda Legal Defense and Education Fund**.

State Policies on HIV Reporting

Where the states stand on HIV case surveillance:

- **Existing policy using names:** Alabama, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Iowa, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, Wyoming.
- **Existing policy using unique identifiers:** Maryland, Texas
- **Moving toward name-based reporting:** Alaska, Delaware, Kansas, Kentucky, New Hampshire, New York, Oregon, Texas, Washington.
- **Moving toward unique identifiers:** Hawaii, Illinois, Massachusetts.
- **Moving toward case surveillance, but undecided about method:** Connecticut, District of Columbia, Georgia, Maine, Montana, Pennsylvania, Rhode Island, Vermont.
- **Status uncertain:** California.

0887-1493/98/$2 + $1.50

ISSUES- HIV Surveillance

(continued from previous page)

Dr. Harold Katner, a member of the state's **AIDS Task Force** and an HIV specialist, said states that use coded identifiers instead of names had trouble collecting complete data.

Kentucky

Since 1990, existing law has allowed physicians to notify state health officials of positive test results using the patient's initials and date of birth, but reporting is not required.

As of June 1998, 2,375 HIV cases have been added to the rolls, but it's not known how many are duplicates and how many infections aren't being reported.

"It's not really a unique identifier system," said **Mollie Adkins**, AIDS surveillance coordinator for the state **Department of Health Service**. "It's not a very good way to do HIV case reporting."

Adkins said the department plans to develop "within a few months" a proposal for HIV case surveillance based on names.

The change requires approval of the state Legislature, which does not meet until January 2000.

Officials aren't sure whether the names of those already diagnosed as HIV-positive would be added to the new registry. Adkins said trying to track down the identities of individuals from their initials and birth dates would be a daunting logistical challenge.

Kansas

A state lawmaker tried earlier this year to attach a name-reporting policy to an appropriations bill *(see AIDS Policy & Law, April 17, page 16)*, but his colleagues shelved debate until 1999.

When the Legislature meets in January, the **Department of Health and Environment** will present a bill calling for name-based reporting, said **Karl Milhon**, director of the AIDS section in the **Bureau of Disease Control**.

"We are having surprisingly little resistance from our communities," Milhon said. "They don't like it, but they recognize the need for keeping track of HIV cases. ... The bottom-line issue is that people aren't against name reporting of HIV cases. The issue is confidentiality."

Milhon said Kansas law already has numerous privacy protections.

Maine

State public health officials are conducting meetings through December to gauge community reaction to HIV case surveillance. At this point, no decision has been made whether to recommend names or unique identifiers, said **Sally-Lou Patterson**, director of the state HIV/STD program.

Any change in reporting policies would be done by administrative rule.

A new rule could be in place in early 1999, after a public comment period, she said.

New Hampshire

Since 1996, the Granite State has been tracking the names of people whose CD4+ T-cell counts fall below 500 and is now beginning the process of moving toward reporting all HIV cases, said **David Ayotte**, chief of HIV/STD surveillance.

Ayotte said a town meeting is scheduled for late fall, and an administrative rule could be in place by early to mid 1999.

Ayotte would prefer a national names-based system. He said a majority of New Hampshire's HIV patients travel to Boston for testing or treatment. If Massachusetts goes to a unique identifier system, their names won't appear on any New Hampshire registry unless they seek treatment locally.

Oregon

The state currently has name-based HIV case surveillance, but only for children under age 6. Physicians send positive HIV test results of adults and adolescents to state health officials on an anonymous basis, making it impossible to weed out duplications or conduct follow-up surveillance.

The state **Health Division** has unveiled a proposal for name-based reporting of all HIV cases, but first will consult with the community in a series of meetings in October or November, said **Steve Mondesitt**, surveillance manager.

"Whatever comes out of the advisory process will supersede the proposal," Mondesitt said. "A few people are ideologically adamant against names reporting, but I don't see it as a broad-based opinion, as much as it is a case of opinions of people who matter."

Mondesitt hopes the meetings will build a consensus for name-based reporting.

The new policy could be in place as early as January 1999.

Pennsylvania

Officially the state **Department of Health** has no position on whether HIV case surveillance would be conducted by names or unique identifiers, but activists opposed to name reporting fear the decision already has been made.

At a news conference Oct. 5, several groups insisted tracking the epidemic by names would discourage people from getting tested.

Among the groups lining up against names reporting are the **Philadelphia AIDS Activities Coordinating Office**, which coordinates public HIV services in a nine-county region; **ACT UP**; several community-based service organizations in the Philadelphia area, and the **American Civil Liberties Union**. ❑

AIDS Policy & Law

The Biweekly Newsletter on Legislation, Regulation and Litigation Concerning AIDS

Route to:

Volume 13, Number 20 October 30, 1998

Discrimination

Appeals Court Set To Re-Examine Dental Bias Case

The next phase of dentist **Randon Bragdon**'s defense of his refusal to treat an HIV-positive patient in his dental office is about to unfold.

The U.S. Supreme Court decided in June that the patient, **Sidney Abbott**, was protected under the Americans with Disabilities Act because of her HIV infection.

However, the court sent the case back to the 1st U.S. Circuit Court of Appeals to reconsider whether Bragdon was legally justified for not treating Abbott in his office on the grounds that he might become infected accidentally.

Now, the 1st Circuit is moving closer to making a decision on that question. The result could have important ramifications for health-care providers and patients alike.

For Bragdon, the issue is whether a health-care provider should be able to use his or her professional judgment in deciding how best to administer care to a patient who has an infectious disease.

He insists that there is enough credible medical evidence to show that he acted properly in refusing to fill the cavity in Abbott's tooth and seeking instead to perform the procedure in a hospital, which he believed would have better safeguards.

Abbott, on the other hand, sees the situation as one of unreasonable fear masquerading as professional judgment. If Bragdon prevails, Abbott's

(See **DENTAL** on page 10)

Panel Urges Universal Testing Of Pregnant Women for HIV

HIV tests should be given to every pregnant woman, and should no longer be contingent on the extensive pre-test counseling now part of standard protocols, a committee of the **Institute of Medicine** said Oct. 14.

The goal of the new policy is to reduce many of the barriers that currently keep women from being tested, said the panel's chair, **Dr. Marie McCormick**, a professor at the **Harvard School of Public Health**.

Patient counseling is "simply too onerous" for health-care providers to undertake for all their patients, McCormick said. As a result, many physicians feel they must choose between exercising independent judgment about who should be tested, or they simply do not test patients they perceive to be at low risk.

"With either choice, providers run the risk of failing to detect a pregnant woman who is infected with HIV," McCormick said.

The conclusions were contained in a report sent to Congress on strategies for reducing perinatal transmission of HIV. They were prepared by a panel of 13 physicians, epidemiologists and ethicists

(See **PREGNANT** on page 8)

Inside this Issue

0887-1493/98/$2 + $1.50

PREGNANT (continued from page 1)

convened by the Institute, which advises the federal government on policy issues.

The committee's central recommendation calls for adoption of a national policy of universal HIV testing, with patient notification, as part of the standard battery of blood tests given to pregnant women as part of prenatal care.

Women would be informed that the HIV test was being conducted, but they would not receive counseling prior to the test. Explicit written consent would not be necessary.

They would have the right to refuse testing. Doctors should not necessarily take the refusal as final, the report said. Providers should assess the clinical circumstances and, in some cases, may wish to counsel women later in prenatal care about the benefits of testing.

"At its site visits, the committee learned of many cases in which pregnant women, later identified as HIV-positive, initially refused testing, but eventually agreed after repeated discussions with their providers," the report says.

"Patients who refuse testing should never be coerced or denied services, and providers should understand that for some women, a positive test may lead to severe consequences, such as discrimination, eviction from housing and domestic violence," the report adds.

Report Outlines Action Plan

The cost of routine testing would be low, if incorporated into standard prenatal testing protocols. The committee estimated the cost at $3 per woman, which, when HIV seroprevalence rates are taken into account, amounts to $51,100 per HIV case detected.

The woman can then take antiretroviral drugs to prevent transmission to her offspring. The lifetime cost of treating one case of pediatric AIDS is estimated at $65,000 to $200,000, according to research studies.

To accomplish the goal of universal testing, the report spells out a series of actions to be taken:

- Health-care plans should implement policies to facilitate routine prenatal testing, and should track their success in conducting HIV screening.

The report urges the **National Committee for Quality Assurance**, which monitors insurers' performance, to adopt standards for HIV screening of pregnant women. In addition, it asks states to upgrade their managed-care contracts for Medicaid providers. Only 18 states mention HIV in their contracts as of 1996, and only one, Florida, specifically assures Medicaid recipients access to antiretroviral therapy as outlined by the AIDS Clinical Trial Group 076 study.

- Businesses and other organizations that purchase health care should support routine prenatal testing in their contracts with health-care insurers.
- Professional medical organizations should update their practice guidelines to recommend routine prenatal testing.
- Providers must be educated about the value of prenatal HIV screening and how to deal appropriately with those who test positive. They need to be aware, for example, that false ELISA readings account for two-thirds of all positive tests in low seroprevalence communities. Confirmatory testing with Western blot or immunofluorescence reduces false positives to nearly zero.
- Health officials need to improve their outreach to pregnant women, to address concerns about testing and treatment.
- Testing should be "seamlessly linked" to treatment for women found to be infected, and the care must be coordinated before, during and after delivery. Providers must take steps to ensure that the patient's confidentiality is protected, and that a patient is not forced to take a test.

Role of the Public Sector

The public sector will play an important role in carrying out a universal screening policy, the report says.

Although roughly 70 percent of women of child-bearing age have private health insurance, usually through their employer, that isn't the case with the subset of women at highest risk of HIV infection. They tend to have lower incomes and less access to insurance.

About 61 percent of women with HIV depend on Medicaid for their medical care. Medicaid also pays for the care of 90 percent of children with AIDS.

States have directed about half of their Medicaid recipients into managed-care plans, which the report says "may well affect the ability of persons with HIV to access services needed for their care."

An estimated 6,000 to 7,000 HIV-positive women give birth annually, or roughly 17 out of every 10,000 pregnancies. Perinatal transmission of HIV accounted for 7,335 cases of pediatric AIDS reported to public health agencies since the epidemic began, including 473 cases in 1997.

Three states – New York, New Jersey and Florida – account for nearly half of the nation's perinatal infections.

Roughly 15 percent of HIV-infected pregnant women, most of them drug users, receive no prenatal care.

Legislation May Be Needed

Most states moved rapidly to implement the existing prenatal HIV testing policy, which was developed by the **Public Health Service** in 1994. It calls for physicians to offer HIV counseling and testing to all pregnant women, and urges them not to deny prenatal care to those who refuse.

(continued on next page)

0887-1493/98/$2 + $1.50

(continued from previous page)

As of June 1998, only Idaho, Kansas and Vermont have neither laws nor policies on counseling and testing of pregnant women, according to a study soon to be published by **Lawrence Gostin** of **Georgetown University Law Center**. The findings appear in the IOM report.

State policies take various approaches. In California, for example, every prenatal provider must by law offer HIV information, counseling and testing. Texas law requires physicians to conduct an HIV test unless the woman objects. Only New York state mandates the testing of newborns.

Next Step is Shalala's

Congress asked for the IOM report when it reauthorized the Ryan White CARE Act in 1996. The legislation requires the secretary of Health and Human Services to determine whether mandatory testing of newborns whose mothers have not undergone prenatal care has become "a routine practice."

If the answer is yes, then states would have to reduce perinatal transmissions by 50 percent from the base year of 1993 if they are to continue receiving Title II Ryan White funding.

HHS **Secretary Donna E. Shalala** has yet to issue such a declaration.

"Right now, it's currently under deliberation within the department," said **Mona Brown**, a spokeswoman for HHS' **Health Resources and Services Administration**, which administers the Ryan White program.

Reaction to the Report

The IOM report has drawn widespread praise, but some concerns were voiced also.

In a statement, an official of the **Centers for Disease Control and Prevention** welcomed the recommendations.

"Despite dramatic progress in recent years in decreasing perinatal HIV transmission, far too many HIV-infected women are not provided the opportunity to get care for themselves and to reduce their child's risk of infection," said **Helene Gayle**, director of the **National Center for HIV, STD and TB Prevention**.

"CDC agrees with the Institute of Medicine's conclusion that mandatory newborn testing would not further the goals of perinatal HIV prevention," Gayle said. "Providing HIV-infected pregnant women the best chance for a healthy baby requires that they be reached early in prenatal care with the opportunity to learn their HIV status and, if infected, to benefit from therapy for their own health and for reducing the risk of transmitting HIV to their infant."

Gayle said pre-test counseling may need to play an important role in prenatal care.

"It is important for a pregnant woman, particularly if she is at high risk for infection, to understand why she should be tested and what a positive test result might mean for her baby," she said.

A leading congressional advocate of routine HIV screening for pregnant women praised the report.

"We should have enacted this policy years ago," said **Rep. Tom Coburn**, R-Okla. "But because we have put politics above good public health, up to 8,000 babies that could have been saved since 1994 will needlessly suffer and die."

Coburn pointed out that the **American Medical Association** already has endorsed universal HIV screening for pregnant women.

"I would call on the **American College of Obstetricians and Gynecologists**, the **American Academy of Pediatrics** and AIDS advocates to follow the lead of the IOM and the AMA and put the health and lives of women and children above unfounded political arguments," he said.

Need for Counseling Seen

AIDS Action expressed its support for universal testing, but voiced concern that without adequate safeguards and physician training, the IOM plan could lead to coercion and abuse.

"Universal voluntary testing must be implemented thoughtfully and with the intent of protecting the health of pregnant women, not tricking them into an HIV test," said **Daniel Zingale**, the group's executive director.

The **AIDS Policy Center for Children, Youth and Families** raised even stronger concerns.

"While we support many of the recommendations made in the report, we object to its recommendation to lower HIV pre-test counseling and informed consent standards for pregnant women," executive director **David C. Harvey** said.

"We were surprised, frankly, that the Institute of Medicine didn't hold doctors to a higher standard," he said.

Mildred Williamson, president of the center and coordinator of the women and children's HIV program at **Cook County Hospital** in Chicago, said current guidelines are working well.

"It is unethical to test a pregnant woman for HIV without informed consent," Williamson said. "Women must fully understand what an HIV test is, and the implications of a positive or negative result. It is not enough to simply inform women that they are being tested for HIV, and put the burden on them to ask questions." ❑

CONTACTS: A summary of the report is available at the Institute of Medicine's web site at www.nas.edu. A copy of the full 290-page report, *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States*, is available for $48.95 plus $4 shipping charges by calling (800) 624-6242.

IN THE FIGHT AINST AIDS

GMHC

Statement on HIV Surveillance

After seventeen years and more than 400,000 deaths, AIDS seems almost unrecognizable from its earliest and darkest days. When the epidemic began, there was little hope for infected individuals. Today, our nation's investment has begun to yield impressive dividends. New drugs, better medical care, physicians trained in HIV disease, and an effective community-based infrastructure have transformed the management of HIV. Thousands of infected individuals are now living longer and healthier lives, and perinatal transmission has been dramatically reduced.

These advances pose a fundamental challenge to the system used to monitor and track the epidemic. They have, in fact, brought us full-circle, back to the beginning, when no one understood the direction, magnitude and gruesome toll of the epidemic. Since 1981, the system for monitoring the epidemic has relied on counting individuals who have AIDS. In the absence of effective treatment, AIDS surveillance was a reasonable surrogate for HIV trends. However, the wide-spread introduction of combination therapies and greater access to medical care have helped thousands remain healthy and AIDS-free for longer periods of time. The current AIDS-based surveillance system is no longer an effective measure of the true extent of the epidemic. Today, as in 1981, we know little about HIV infection trends, and this lack of information is endangering lives and undermining our efforts to fight the epidemic.

Surveillance data play a crucial role in battling the epidemic. Surveillance data help answer vital public health questions, such as the number of infected individuals in the United States, behavioral risk factors for infection, and emerging trends among individuals with newly acquired infection. Surveillance data can also help assess the course of disease among the infected by monitoring health care usage, disease severity, number of deaths, and characteristics of those for whom treatment fails. Surveillance data are also crucial for the design, conduct and evaluation of HIV prevention programs. Surveillance data can be used to allocate resources to hard-hit regions and communities.

Recommendations

1. GMHC calls on New York to implement a system for monitoring HIV infections. A new surveillance system for the epidemic should count the number of people who are infected with HIV in addition to the number of people who have AIDS. HIV surveillance should be designed to generate accurate, useful, complete and timely data on infection trends, and should inform our efforts to battle HIV. The implementation of a new HIV surveillance system must include the following:

- **Involve affected communities in the development of a new surveillance system.** New York must seek the participation of all communities fighting the epidemic in this process.

- **Assure strong privacy safeguards.** New York's strongest confidentiality protections, which now shield the AIDS-based surveillance system, must be applied to HIV data collected by public health officials. New York's AIDS surveillance system has operated without breaches of confidentiality for almost two decades. A new HIV-based surveillance system must be protected in a similar manner.

- **Evaluate and implement a "unique identifier" system.** An anonymous, coded system of unique identifiers should be developed for HIV surveillance because it will offer the strongest protections for patients' privacy. New York already uses unique identifiers for monitoring other conditions. Maryland and Texas have unique identifier systems for monitoring HIV infections. These models should be examined to develop an appropriate system for HIV surveillance in New York.

- **Re-evaluate the type of data collected by New York's public health officials.** The current surveillance system provides limited data on the populations most at risk. A new surveillance system should be enhanced to collect better data on more people so programs can be targeted to communities that need the most help

- **Oppose linking HIV surveillance to non-surveillance activities.** HIV surveillance is a research activity conducted by epidemiologists. Linking surveillance to non-surveillance activities, such as mandatory partner notification, contact tracing, and the criminal justice system will jeopardize the implementation of a new surveillance system and will drive infected individuals away from HIV counseling and testing.

- **Preserve free, publicly-funded anonymous testing.** Anonymous testing is an important vehicle for some people to receive counseling and testing, enter medical care, and prevent further transmission. Anonymous testing is an important adjunct to surveillance, because lack of this option leads some people to delay testing, donate blood as a means to be tested anonymously, and give false information at confidential testing sites.

2. GMHC calls on New York City, New York State and the federal government to enhance their funding and commitment to ending this health crisis. Monitoring HIV infections will benefit people infected with HIV only when it is linked with appropriate medical and human services.

- **Guarantee health care to all people who are infected with HIV.** Government must assure that Medicaid, AIDS Drug Assistance Programs, and private health insurers offer comprehensive health care to all infected individuals, in accordance with the new Public Health Service's HIV treatment guidelines.

- **Expand HIV prevention efforts and target high-risk populations.** HIV prevention is our only weapon against this epidemic. Yet, for most of the

epidemic, government-funded prevention programs have not targeted the populations most at risk. In fact, federal funding for prevention targeted to gay men was illegal until 1992, and federal funding for needle exchange remains illegal today. Adolescents, young gay males, people of color, women, and injection drug users have been ignored by government-funded prevention programs, and the cost of this ignorance is stark and shameful.

- **Promote HIV testing.** Since HIV testing is the crucial first step for an infected individual to begin taking charge of his/her health, government at all levels must aggressively promote HIV testing to communities at highest risk through print, radio, television, and community-based programs. Promotion of HIV testing should include information on the value of testing, the different testing options available, including anonymous testing, and the confidentiality protections afforded HIV test results.

- **Enact federal and state confidentiality protections for medical records.** Although public health data, such as AIDS and HIV surveillance, are protected by state and federal statutes, medical records are widely shared such that today private medical information is too easily available. Individuals must be assured that their private health information will be held in the strictest confidence.

Summary

Recognizing the important role HIV surveillance can play in our national strategy against the epidemic, GMHC strongly urges New York to implement HIV surveillance. GMHC calls for a compassionate and considered process for implementing HIV surveillance. GMHC believes this is an opportunity for all communities to make stronger their commitments in battling this health crisis, and calls on all levels of government to increase their funding and commitment.

SAN FRANCISCO AIDS FOUNDATION 995 MARKET STREET, SUITE 200, SAN FRANCISCO, CALIFORNIA 94103
VISITORS' ENTRANCE: ONE 6TH STREET AT MARKET

June 26, 1998

Dear Colleague:

Enclosed please find information on HIV surveillance and reporting that we thought you might find useful in the coming months as this issue continues to be discussed and debated in Sacramento and Washington, D.C.

Most HIV advocates, including the San Francisco AIDS Foundation, strongly oppose mandatory reporting of HIV infection by name because of the potential for such systems to deter individuals from HIV testing and treatment. Several studies have shown that this deterrent effect is particularly strong among those groups at highest risk for HIV infection in California, including gay men. The results of these studies are summarized in the enclosed fact sheet entitled, "Mandatory Names Reporting of HIV Infection Is a Deterrent to Testing and Medical Treatment."

Because of the public health concerns raised by names reporting, AIDS advocates nationwide are urging the adoption of a non-names based HIV reporting system that protects patient confidentiality by reporting positive test results to public health officials through the use of a unique identifier or code, rather than by name. In addition to California, states that have implemented such systems, or are in the process of considering these alternatives to names reporting include Maryland (which has been very pleased with the data they have obtained from their unique code system), Massachusetts, Hawaii, Washington and Connecticut. This mailing also includes a copy of "An Activist's Guide to Unique Identifiers," which was written by Anna Forbes, an AIDS and health policy consultant from Philadelphia.

Here in California, a group of advocates and public health officials, which includes the AIDS Foundation, AIDS Legal Referral Panel, Project Inform, AIDS Project of the East Bay and the City and County of San Francisco, have formed the California HIV Surveillance Coalition. This group is now working with Assemblywoman Carole Migden (D-SF) on state legislation that would create an HIV Surveillance Task Force to develop an HIV case reporting system that is non-names based. The most current version of this legislation is enclosed. We are hopeful the bill will be passed by the Legislature and will ultimately be enacted by Governor Wilson.

In related news, San Francisco Mayor Willie Brown, Jr. recently convened a two-day, national consultation on the issue of non-names based HIV reporting. Representatives of various states throughout the country that are considering alternatives to names reporting attended the meeting. The goal of the meeting was to assist the City of San Francisco in developing a reporting system that could potentially be a model for California or other states to consider. Local members of that body will continue to meet in the upcoming months to help design a system that potentially could be field-tested in some settings in the City.

As states and localities continue to consider this issue, we are hopeful that the U.S. Department of Health and Human Services (HHS) will ensure that any federal guidelines issued on this topic allow states to implement reporting systems that best meet individual state's needs. The AIDS Foundation recently sent a letter to HHS Secretary Donna Shalala, which is enclosed, encouraging her to ensure that federal guidelines provide states with maximum flexibility and equal support to implement alternative systems. Please feel free to use the enclosed letter as a model for a similar letter from your own organization or community planning body. In addition, the United States Conference of Mayors recently passed a resolution, authored by Mayors Willie Brown, Richard Riordan (Los Angeles), and Thomas Menino (Boston), urging HHS to issue guidelines that offer states flexibility in developing their HIV surveillance systems. A copy of this resolution is also enclosed.

We hope that you find the enclosed information useful in your own advocacy on this important issue. If you would like further information about any of these documents or about HIV surveillance in general, please feel free to contact the Public Policy Department at (415) 487-3081.

Sincerely,

Regina Aragón

Regina Aragón
Deputy Director for Public Policy

Fred Dillon FA

Fred Dillon
State Policy Associate

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

June 3, 1998

The Honorable Donna Shalala
Secretary, Department of Health and Human Services
200 Independence Ave., S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

I am writing to express the San Francisco AIDS Foundation's concerns regarding the Centers for Disease Control and Prevention's (CDC) unpublished, draft guidelines for HIV case surveillance. While the AIDS Foundation fully supports efforts to more accurately track the scope of the HIV epidemic, including the use of HIV case reporting, we are opposed to HIV names reporting and believe that, at this time, it is critical for your office to intervene to ensure that the CDC guidance provides states with maximum flexibility and equal support to implement alternative systems.

This flexibility is extremely important for California, which is currently considering legislation to implement a non-names based HIV surveillance system. Because of the recognized need for improved surveillance, as well as the negative public health consequences of HIV names reporting, the California HIV Surveillance Coalition—a collaboration of over 40 community-based health and HIV organizations throughout California—has strongly advocated for the development of a non-names based HIV reporting system. The Coalition is currently working with Assembly Member Carole Migden on passage of her bill related to non-names based HIV reporting, AB 1663, which has the support of the California Medical Association.

As you know, work is also taking place at the local level here in San Francisco. Based on the Mayor's Summit on AIDS and HIV, which was held earlier this year, Mayor Willie Brown, Jr. is convening a task force of local and national experts to develop a non-names based HIV reporting system. The system that is crafted will be implemented in the City of County of San Francisco, and hopefully used as a model for California and other states. This group is scheduled to meet June 11-12.

Several other states are also considering non-names based reporting systems, including Massachusetts, Washington, New York, and Hawaii. All of these jurisdictions must be given the opportunity to craft systems that are not fraught with the negative consequences of names based reporting. Additionally, HHS must ensure that federal resources are distributed equitably to support a range of state determined surveillance systems.

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

State self-determination regarding the diseases that should be reported and the mechanism by which this reporting should be done has long been a hallmark of our nation's public health efforts and disease surveillance activities. States must be provided with the opportunity to craft systems that will provide helpful data without causing individuals at greatest risk for HIV to fear testing and care settings.

It is our belief that names-based HIV reporting will deter individuals from HIV testing and care, thereby undermining efforts to accomplish our shared goal of ensuring early and consistent access to HIV therapies (please see the attached fact sheet on research on this topic). Contrary to the CDC's assertions, *names* are not needed to obtain useful data on the epidemic, nor are names necessary to link individuals into care, which is more appropriately a function of HIV counseling and testing programs.

In closing, we would also ask that the Department clarify that more widespread use of non-names based systems of HIV surveillance would not threaten states' funding, or undermine the integrity of national surveillance, as is often suggested by CDC officials. There is absolutely no justification for the CDC's threat to states that a decision to adopt a non-names based reporting system will compromise federal funding that is tied to caseloads. If statistical sampling techniques can be used to adjust for undercounting by the Census Bureau, they can certainly be used to ensure that states are not penalized for using alternative approaches to HIV case surveillance.

Thank you very much for your attention to this important matter. Please feel free to contact me at (415) 487-3099 if you have any questions regarding our concerns or the progress in California in developing a non-names based system.

Sincerely,

Regina Aragón

Regina Aragón
Director of Public Policy

cc. Kevin Thurm
Dr. David Satcher
Dr. Eric Goosby
Dr. Helene Gayle
Sandy Thurman
Marsha Martin
Chris Jennings

The United States Conference of Mayors

Resolution No. 38

Submitted By:

The Honorable Willie L. Brown, Jr.
Mayor of San Francisco

The Honorable Thomas M. Menino
Mayor of Boston

The Honorable Richard Riordan
Mayor of Los Angeles

HIV SURVEILLANCE SYSTEMS

1. **WHEREAS**, the Centers for Disease Control intends to issue guidelines recommending that all states adopt a name-based HIV surveillance system; and

2. **WHEREAS,** we support the development of HIV surveillance systems, but believe that state public health officials must be free to choose their own HIV surveillance systems based on the needs of their own communities and the best judgement of state and local public health officials; and

3. **WHEREAS,** states self determination has long been the hallmark of our nation's public health efforts and disease surveillance strategies; and

4. **WHEREAS,** legitimate concerns exist regarding the deterrent effect of names reporting on voluntary testing and treatment among high risk populations.

5. **NOW, THEREFORE, BE IT RESOLVED** that the Centers for Disease Control must be directed to conduct well-designed, published scientific research on surveillance systems and names reporting; and

6. **BE IT FURTHER RESOLVED** that the Center for Disease Control should issue guidelines that offer states flexibility to develop HIV surveillance systems, supporting the development of name- or non-name based systems, and only after such scientific research is completed; and

7. **BE IT FURTHER RESOLVED** that federal resources must be distributed equitably to support a range of state determined surveillance systems.

Projected Cost: Unknown

An Activist s Guide to Unique Identifiers

By Anna Forbes, MSS

In its recent position paper "Monitoring of the HIV Epidemic," NAPWA expresses guarded support for HIV case reporting "only using unique or coded identifiers that insure privacy and confidentiality of the individual."

So what are these unique identifiers people are talking about? How do they work? Since just about any code can be cracked, why should I trust them to protect my privacy?

These are the very legitimate questions I'll try to address in this article.

Unique identifiers (UIs) are nothing new. We use them every day in the form of telephone numbers, zip codes, credit card numbers, product serial numbers, etc. Any number or letter-number code that has a one-to-one correspondence to a given person, thing or location is a UI. Your telephone number, for example, only rings in your house. When people call you, they don't have to be concerned that the phone will ring in someone else's house (assuming that they dial correctly) because your phone number corresponds with your phone on a one-to-one basis.

For HIV case reporting, we need a UI that has a couple of other important characteristics. Specifically, it needs to use common data elements, be reproducible and have a low duplication rate.

Aaaaaghhh.....techno-speak!!!
What does all that mean?

Relax. Remember, you are the people who taught yourselves how drugs work (and don't work) in the body. This is nowhere near as difficult as that.

DATA ELEMENTS are the chunks of information that UIs are made out of. Maryland has a UI system for HIV case reporting, for example, in which the data elements are the last four numbers of a person's Social Security number plus his/her birth date and codes indicating race and gender. The testing provider arranges these data elements in a specific way to produce a twelve-digit UI code. The code gets attached to the person's blood sample before it goes to the lab for HIV testing.

Now, we have public data elements and private data elements. Public data elements are pieces of information about you that show up in public records all the time, such as birthdate, race, gender, Social Security number, etc. Every time you turn around, someone is requiring you to list that information on a form and then entering it from the form into a database. The information pieces that shows up at the Department of Motor Vehicles, birth and death registries, Social Security registries, etc. are public data elements.

Private data elements, on the other hand, are pieces of information that don't show up in public databases. They're also called "keys". The private word, initials or set of numbers you use to access your account when you go to an automatic teller machine is a good example of a key. You control it. Even if somebody steals your bankcard, he or she can't get into your account without your private key. More about these later.

When you select common data elements to use in a UI system, you're looking for pieces of information that everyone has, that don't change over time and that people don't mind giving at HIV test sites. This can be trickier than it sounds. Maryland chose to use last four digits of the Social Security number, for example, not realizing the extent to which people either didn't know their Social Security number, didn't have one or didn't want to give it out. In retrospect, the Maryland folks believe that their system (which works well, overall) might work even better if they hadn't selected this particular data elements.

Having a REPRODUCIBLE UI is important because, without it, people tested more than once will be assigned a different UI each time they are tested. This results in undetectable duplications -- people listed in the HIV registry more than once -- which throws off the accurate epidemiological picture we are trying to obtain of how many people are living with HIV and in what populations. This is also why random or sequential numbers don't work. They can be used to count the number of tests done but can't count the number of individuals tested with any accuracy.

LOW DUPLICATION RATE means that is very unlikely that two people will be assigned the same UI. Duplication can't be eliminated entirely (even name reporting has some duplication) but it can be reduced by using a good UI system. SOUNDEX (frequently used as a UI system even though it's not technically a UI) has a duplication rate of approximately ten to twenty percent --- too high by most people's standards.

By contrast, the Unique Record Number System (designed by HRSA, the federal entity that administers the Ryan White Care Act) has a duplication rate of only .02% - .04% -- an acceptable rate in most people's books. The duplication rate you get depends on the data elements you select and the rules you establish (also called the algorithm) for creating the UI.

This sounds really complicated. Do UIs actually work? Is anyone using them?

YES! They are being used successfully in a number of settings to protect health-related information (not to mention being used constantly in the banking/business side of life). Maryland is already using them for HIV case reporting and Massachusetts has announced its intention to pilot a UI for its HIV surveillance. However, Texas was not happy with the performance of its UI and is considering adopting name reporting. They are considering this mainly because their system is desperately underfunded and because they've had a low level of "buy-in" by providers and local health departments.

Maryland's UI system is also underfunded. But both the Health Department and the consumer/advocacy communities view it as a success. It enables the Health Department to collect and track information without causing testing avoidance or putting the privacy of people living with HIV at risk. Maryland is already using the information it has collected through the UI system to make funding allocation decisions and plan targeted prevention and care programs.

UI-based (as opposed to name-based) HIV case reporting systems are also in place in Australia, Denmark, Belgium and the United Kingdom. And beyond HIV, states also using
UIs to protect people's privacy in all kinds of sensitive, health-related situations.

New York state, for example, uses a UI in place of the woman's name on "fetal death certificates" (documentation of miscarriages and abortions). In Massachusetts, the state Health Department uses UIs on the records of people receiving state-funded mental health care. Pennsylvania, similarly, uses UIs in place of names to aggregate information about people receiving services through the state Office of Drug and Alcohol Programs. So there's nothing new or unusual about the idea of using UIs to track health care information.

But can't UIs be cracked? Why should I trust them?

Imagine a big, long line. Put "absolute privacy" on the right end of the line and "no privacy at all" on the left end. All UI systems fall somewhere along that line, between the two extremes. Put Social Security numbers on the left end next to "no privacy at all" because, as we all know, if you have a Social Security number, then practically everybody has it on file. It's a UI but it's not one that guarantees any privacy.

Near the right end you can put UIs that combine a key (private data element) with the public data elements discussed above. UIs made entirely of public data elements fall along the middle of the line.

Computerized encryption systems give you somewhat more security than manual ones because more complex algorithms are harder to crack manually than simple ones. Since a computer can whiz through the process of encrypting (mixing up) the information, it can handle really fancy algorithms that have lots of steps in the same amount of time as it takes a human to carry out a simple algorithm. This means that a computer encrypted UI is less likely to be cracked by someone who is just trying to do it casually (a curious "browser" who somehow gets obtains a list of UIs). Even computer encrypted UIs, however, can be cracked by someone with a computer and access to the UI algorithm.

People tend to assume that computer encrypted UI systems are too expensive, too difficult and would require every HIV testing provider to have a computer on site. But what if you used a centralized, call-activated computer that providers accessed via touch-tone phone? The provider could call up the computer and punch in the necessary data elements using the dialing buttons. The computer at the other end could crunch up the data and read back the UI. How hard is that?

OK, I get that. But what are those UIs all the way on the right about?

They're the ones that are more secure because they include a key (private data element). Here's how they work.

Imagine that you're trying to crack a UI system (Mission Impossible music rises in the background). No matter how good the encryption, any system that uses only public data elements can be cracked. You just need three things:

1) A computer;
2) A secondary data base that has all the necessary data elements in it; and
3) A copy of the algorithm used to produce the UIs.

Your secondary database could be Social Security records, a drivers license registry or anything that shows the data elements required for that particular UI system. You process the secondary database through the algorithm to produce a UIs for each of the names on the secondary database. Then you just cross-match those UIs against the original list of UIs you're trying to crack. Every time you find a match, you've identified a person on the original list of UIs. This is called "cracking by cross matching".

Now (take a deep breath, we're almost out of the technical part), what if the UI system you're trying to crack is one that scrambles a key in along with the public data elements? Remember the key is a private word or number that won't show up in a public record's database. If it's a keyed system, you might as well take off the black ski mask because you won't be able to generate the second set of UIs. The public records database can't provide all the data elements you need to produce the UI because it doesn't include the keys. Incorporating a private key selected or controlled by the consumer effectively jams any effort to crack the UI system by cross matching.

Given all this, you'd think that people committed to privacy would automatically want to use keyed UI systems for HIV case reporting. BUT... because they can't be cracked by cross matching, they also can't be used to cross-match HIV data against other, relevant databases such as:

- The AIDS registry (to prevent having a lot of people listed twice, once on the HIV list and again on the AIDS registry);
- The national death registry (to make sure that people who have died are removed from the HIV registry so that it's current); and even
- The ADAP records (to find out what proportion of people with HIV in your state are in the state's ADAP program).

In both Maryland and Texas, the process described above is exactly how they determine how many of the people in the HIV registry are also in the AIDS registry, the ADAP registry, etc. They produce UIs for everyone in those registries and then cross match those UIs against the HIV registry. But if states use a keyed UI system for HIV reporting, they won't be able to generate UIs for that second database because they'll be missing one of the necessary data elements.

How important is that?

Only you and your state can decide.

What I recommend to states seriously considering this issue is that you form a Working Group that includes people with HIV/AIDS, Health Department personnel, HIV counseling and testing providers and one or more UI experts to serve as technical advisors. Selecting a UI system is like buying a car -- you have to consider and discuss the advantages and disadvantages of a lot of models before choosing what you need and can afford.

The Working Group needs to ask itself these questions:

1) What data elements don't change over time and are supplied without objection?

2) What's the highest level of confidentiality we can agree on?

Is the state insisting that our UI system has to be one that can be cross-matched against other data bases? Can we come up with a way to get the ancillary information we need while using a keyed UI system for HIV case reporting? Can we agree to "grandparent it in" (i.e. start assigning keyed UIs to everyone with HIV/AIDS with the understanding that, eventually, the AIDS registry and ADAP registries will be made up entirely of people with keyed UIs so we can cross-match at least those registries against the HIV list)?

3) What's the highest level of confidentiality we can afford?

Adopting any kind of HIV case reporting system is going to cost money. Maryland is spending about $100,000 per year to process 7500 UI reports of HIV infection. New York State, in comparison, is spending at least $200,000 per year solely to support the five additional staff they had to add to 14,400 name-based reports of CD4 counts below 200. The two systems are comparable in cost.

4) Is the system we're considering user-friendly enough that providers will comply when required to use it?

This is a tough set of questions and the Working Group may have to sweat to hammer out an acceptable compromise. Like all good compromise, it will probably make both sides a little unhappy.

You may not get as much privacy protection as you want and the Health Department will have to cope with a system that, let's face it, isn't going to be as easy for them to use as name reporting would be.

Remember that my recommendation is that the UI expert(s) should be there as a technical advisor only. The Working Group should think carefully about the first three questions before

continued on page 10

Unique IDs

continued from page 7

addressing the fourth. Technology should serve people; people shouldn't have to conform to the technology. Once you figure out what you want, it's the UI expert's job to find or create a system that meets your requirements and that is user-friendly enough for providers. Don't let yourself get bulldozed into a system that doesn't work for you.

Above all, don't let anyone tell you that implementing an UI-based HIV case reporting system in your state is impossible. Would you look at a Volkswagen Beetle, decide it's too small, look at a Mercedes, decide it's too expensive and, on that basis, decide that you don't really want a car? Heck, no! You'd just keep shopping!

Finding the right UI system and getting your state to use it may be a labor intensive advocacy process but think about it. Isn't your privacy worth it?

ACKNOWLEDGMENT: With sincere thanks to Walter Cuirle, who taught me practically everything I know on this subject.

MANDATORY NAMES REPORTING OF HIV INFECTION IS A DETERRENT TO TESTING AND MEDICAL TREATMENT

An HIV test is the first step a person must take to learn their health status, and take appropriate measures to stay healthy. The Centers for Disease Control & Prevention (CDC) estimates that over a third of those infected in the U.S. do not know their HIV status. The current clinical guidelines recommend initiating treatment as early in the course of disease as possible to obtain the maximum benefit. Therefore, people at risk of HIV infection should be encouraged to find out their HIV status as soon as possible after exposure to make informed treatment decisions, and any barriers to testing should be removed as quickly as possible.

Changes in the epidemic have led to increasing concern that existing AIDS surveillance efforts are becoming outdated, and a call for an expanded HIV reporting system. The San Francisco AIDS Foundation acknowledges the need for improved HIV data. However, we strongly disagree that HIV *names* reporting is necessary, and we do not believe that the benefits of names reporting outweigh the potential deterrence from HIV testing and/or treatment.

All Studies on HIV Names Reporting Have Shown a Deterrent Effect on HIV Testing

Research on the impact of mandatory names reporting on testing has shown that:

- A 1997 study in anonymous test sites in San Francisco found that 68% said they would not be willing to get tested if their name would be reported to the government. (Woods, 1997)
- The 1996 HIV Testing Survey (HITS) showed that 19% of those surveyed who had never been tested said that the fear that their name might be reported to the government was a factor in their decision not to get tested, after reasons such as fear of finding out, or believing that they were not at risk. For 2% fear of reporting was the main reason. (Hecht, 1997)
- The same survey reported that 18% of those who had delayed testing did so because of fear of being reported to the government, with 3% citing it as the main reason. (Hecht, 1997)
- A 1995 survey done in HIV testing centers in Los Angeles showed that 86% of participants would not have been tested if they knew that their name would be reported to the government. (Reed, 1996)
- A 1989 study in California reported that over 60% of individuals would not get tested if the results were reported. (Kegeles, 1989)

An AIDS Health Project survey in San Francisco (Woods, 1998) shows that when names reporting is explained the deterrent effect is reduced somewhat, but the majority of individuals still indicated that they would avoid testing if names reporting were implemented:

- Of the 68% who said they would not get tested if their name were reported, 12% changed their minds about getting tested once the public health benefits of reporting were explained to them, but a 58% majority continued to oppose testing.
- If the benefits were explained **before** the question about testing was asked, 46% reported that they would not test if names were reported.

A 1998 survey of clients of the San Francisco AIDS Foundation found that 33% of clients would have avoided testing and another 11% would have delayed it if their name were reported confidentially to a government health agency.

Produced by the San Francisco AIDS Foundation
May 1998

Few people in the HITS study reported that their worries about names reporting were the main reason they had not gotten tested earlier, but a significant number said that it had an effect on their decision. The main reasons they did not test were that they were afraid to find out, that they thought they were not at risk, or that they didn't want to think about it. Those are all very personal reasons, which anyone getting tested must consider. Although education campaigns or good counseling can help individuals think through these barriers, they are not the result of a governmental action. The reporting of names, however, is the one cause of delayed or avoided testing which the government can eliminate, by not asking for names as HIV surveillance.

The HITS study also shows that some individuals may not know whether or not their state requires names reporting. However, a lack of information on names reporting policies does not imply that those policies will have no effect on behavior once people learn what the relevant policies are in their states. The San Francisco AIDS Foundation believes that individuals should have adequate information about the policies in effect in their state when they choose to be tested so that they may make informed decisions regarding HIV testing.

The studies cited here may disagree on the degree of deterrence to testing, but they **all** reflect some level of deterrence.

Those at Highest Risk for HIV Infection Are Most Likely To Be Deterred From Testing By Names Reporting

Research has shown a strong deterrent effect in groups which are at high risk of infection, and when high risk groups have been compared to lower risk groups, the deterrent effect is higher for those groups at highest risk. It is also high among communities which have been disproportionately affected by HIV infection, including gay/bisexual men, African-Americans and Latinos. Many of the groups at highest risk of infection, including injection drug users, sex workers, men who have sex with men, and groups which have disproportionate rates of infection, such as African-Americans and Latinos, have a long-standing (and in many cases reasonable) distrust of government, and names reporting would only exacerbate those concerns.

- In the 1995 Los Angeles study, 91% of gay men surveyed reported that they would not get tested if there were names reporting, compared to 86% of all study participants. (Reed, 1996)
- In the same study, participants who self-identified as being at high-risk were significantly more likely to avoid testing under names reporting. (Reed, 1996)
- A 1989 study from UCSF showed that names reporting would reduce the number of gay/bisexual men willing to be tested (Kegeles, 1989).
- Other studies have shown that names reporting would have a significant impact on African-American and Latino testing rates (Fordyce, 1989)
- In South Carolina, when anonymous testing was ended, the number of gay men getting tested dropped by 51%. HIV positive results dropped by 43%, suggesting that many of those who were positive were not getting tested at all (Johnson, 1988).
- In a 1992 survey 77% of gay & bisexual men reported that not wanting their name to be on a government list was one of the most important reasons for not getting tested. (Meyers, 1993)
- A 1994 study in Arizona showed that men who have sex with men delayed testing until anonymous testing was available due to a fear of being reported. It also showed a significantly higher rate of HIV infection among those who delayed testing. (Hirano, 1994)

Produced by the San Francisco AIDS Foundation
May 1998

HIV Names Reporting Will Delay, Not Improve, Access to Treatment For Many People With HIV

Names reporting would also deter individuals with HIV from accessing medical treatment for their HIV infection. The available research shows that:

- In the Los Angeles survey, 23% of those getting tested said that they would not access medical care until they became sick, if name-based reporting were implemented. (Reed, 1996)
- In the same study, when individuals who were HIV-positive were asked what they would have done had their names been reported when they accessed care, 25% said that they would have waited until they were sick, and another 36% said that they might not have accessed treatment at all. (Reed, 1996)
- The AIDS Patient Survey showed that people access care later in states with names reporting than in states without it. Specifically, CD4 counts were significantly lower in names reporting than non-names reporting states. (Bindman, 1997)
- In the same study, of those who delayed accessing care more than a month after testing positive, 10% cited fear of being reported to the government as a reason. (Bindman, 1997)
- The San Francisco AIDS Foundation 1998 Client Survey found that 12% of those surveyed said they might not have sought treatment if they knew that their name would be reported to health officials when they sought medical care, and another 29% said they would not have sought treatment unless they were very sick.

The success of new combination treatments has been used as a justification for names reporting, on the grounds that names reporting will somehow ensure access to treatments, and that expanded surveillance is needed to compensate for people with HIV not getting sick enough to be diagnosed with AIDS. In fact, one of the largest implications of the new treatments is that everyone infected with HIV should get treated as soon as possible in the course of infection, and to do that, they must know their HIV status. If names reporting serves as a barrier to testing, then we lose more than we gain. A better understanding of the epidemic is important, but not at the cost of expanding the epidemic.

Unique Identifiers: A More Sound Public Health Alternative to HIV Surveillance

The primary HIV surveillance system that is considered an alternative to names reporting is unique identifier reporting. Under such a system, an HIV-infected individual would not be reported by name to public health officials but rather by some form of a unique code that could not be traced back to the person. Unique identifiers would address some of the confidentiality concerns and HIV testing deterrence caused by name-based reporting, and still help meet the need for improved surveillance of HIV disease.

Unique identifier reporting has been seen as a potential compromise between those who strongly believe that better HIV data is needed and those who have strong public health and privacy concerns regarding HIV names reporting. Unique identifiers, if designed and implemented properly, are as specific as names in enabling unduplicated counts of people living with HIV, yet do not create a list that could potentially be used to identify individuals. Unique identifiers are currently in use in Maryland and Texas, and are under consideration is a number of other states, including Massachusetts, Washington, Hawaii, and California.

Produced by the San Francisco AIDS Foundation
May 1998

REFERENCES

Bindman, AB, et al., *The AIDS Patient Survey: Assessing the Effect of State HIV Testing and Reporting Policies on the Health Care Seeking Behavior of People with AIDS*. Presentation for the American Public Health Association Conference, Session 3108 (1997)

Fordyce, E, et al., *Mandatory Reporting of HIV Testing Would Deter Blacks and Hispanics from Being Tested*, 262 JAMA 349 (1989)

Hecht, FM, et al., *Named HIV Reporting: HIV Testing Survey (HITS)*. Presentation for the American Public Health Association Conference, Session 3108 (1997)

Hirano, D, et al., *Anonymous HIV Testing: The Impact of Availability on Demand in Arizona*, 84 AJPH 2008 (1994)

Johnson, WD, et al., *The Impact on Mandatory Reporting on HIV Seropositive Persons in South Carolina*, Presentation for the IV International Conference on AIDS (1988)

Kegeles, S, et al., *Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It Under Other Circumstances*, AIDS, 1990: 4:585-588.

Meyers, T, et al., *Factors Affecting Gay and Bisexual Men's Decisions and Intentions to Seek HIV Testing*. AJPH, May 1993, Vol.83, No.5.

Reed, G, et al., *The Impact of Mandatory Name Reporting on HIV Testing and Treatment*, Poster Presentation for the XI International Conference on AIDS (1996)

San Francisco AIDS Foundation, *Client Survey Report on Names Reporting*, April 1998

Woods, WJ, et al., *Names Reporting of HIV-Positives Would Reduce HIV Testing Among Men Who Have High-Risk Sex With Men in San Francisco, CA*, Submitted to the XII World AIDS Conference (1998)

RESOURCES

AIDS Action Committee (Boston), *Creating an Effective Public Health Response to the Changing Epidemic: Moving to HIV Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems*, October 1997

American Civil Liberties Union AIDS Project, *HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties*, October 1997

Burris, Scott, "Driving the Epidemic Underground? A New Look at Law and the Social Risk of HIV Testing," *AIDS & Public Policy Journal*, Summer 1997

Forbes, Anna, "Naming Names: Mandatory Name-Based HIV Reporting, Its Impact and Alternatives," *AIDS Policy & Law*, May 1996

Governor's Advisory Council on HIV/AIDS (Washington State), *HIV Reporting Task Force Report*, January 1998

San Francisco AIDS Foundation, *HIV Surveillance and Reporting Statement*, October 1997

Produced by the San Francisco AIDS Foundation
May 1998

AMENDED IN SENATE JUNE 18, 1998

AMENDED IN ASSEMBLY APRIL 2, 1998

CALIFORNIA LEGISLATURE—1997–98 REGULAR SESSION

ASSEMBLY BILL No. 1663

Introduced by Assembly Member Migden
(Coauthor: Senator Burton)

January 12, 1998

An act to add Section 121040 to the Health and Safety Code, relating to communicable diseases.

LEGISLATIVE COUNSEL'S DIGEST

AB 1663, as amended, Migden. HIV test results: public health reporting: unique identifier method.

Existing law requires public health records relating to acquired immune deficiency syndrome (AIDS) containing personally identifying information that were developed or acquired by state or local public health agencies to be confidential and prohibits these records from being disclosed, except that state or local public health agencies may disclose personally identifying information to other local, state, or federal public health agencies or to corroborating medical researchers, if the confidential information is necessary to carry out the duties of the agency or researcher in the investigation, control, or surveillance of disease.

~~This bill would require the State Department of Health Services to conduct a study to determine the most effective method of conducting public health reporting of human immunodeficiency virus (HIV) tests results by unique identifier method without the use of names. The bill would require the department to report the results of the study to the Legislature.~~

This bill would establish an HIV Surveillance Task Force with a specified membership. The bill would require the task force to develop a uniform, statewide system to report cases of HIV that would be based on a unique code or other method that does not report the names of individuals infected with HIV. The HIV surveillance reporting system would consist of designated components and commence surveillance of HIV cases January 1, 2000. The bill would require, on or before January 1, 2003, the department to commission an evaluation of the department's implementation of the HIV surveillance reporting system.

Vote: majority. Appropriation: no. Fiscal committee: yes. State-mandated local program: no.

The people of the State of California do enact as follows:

~~SECTION 1. Section 121040 is added to the Health~~

SECTION 1. The Legislature finds and declares all of the following:

(a) Improved surveillance of the human immunodeficiency virus (HIV) epidemic will improve state and local efforts to plan for future health care and social services needs, target HIV prevention efforts, and assess needs for additional resources to fight the HIV epidemic.

(b) Effective HIV public health strategies rely on individuals voluntarily seeking testing in a system that protects their confidentiality. Surveillance efforts must be designed to prevent deterrence to HIV testing and treatment of individuals who are infected with or at risk for HIV.

(c) Names-based HIV reporting has been found to deter individuals, particularly those at highest risk for HIV infection, from testing for and treatment of HIV. Therefore, individual HIV cases should only be reported by an alternative system such as one that uses a unique

code that does not deter individuals from testing or treatment.

(d) Although HIV case reporting provides additional data about the epidemic, it does not replace existing surveillance methods such as incidence and prevalence studies. A range of surveillance methods must be employed to provide comprehensive information about the epidemic.

(e) Access to anonymous HIV antibody testing has proven to increase the number of individuals who seek HIV testing by guaranteeing the privacy of test results. Any surveillance system must ensure the continued funding and accessibility of anonymous HIV testing sites.

(f) To promote the goals of surveillance to inform prevention, health care and social service planning, resources allocation, and evaluation of efforts to combat the HIV epidemic, community planning bodies and consortia, local health departments, and other appropriate planning and advisory groups must receive surveillance data in a timely manner.

SEC. 2. Section 121040 is added to the Health and Safety Code, to read:

121040. (a) Surveillance of HIV cases may be conducted pursuant to this section using a uniform, statewide system that reports cases of HIV based on a unique code or other method that does not report the names of individuals infected with HIV.

(b) There is hereby created an HIV Surveillance Task Force that shall develop a uniform, statewide HIV surveillance reporting system.

(c) The HIV surveillance reporting system developed by the HIV Surveillance Task Force shall commence surveillance of HIV cases January 1, 2000. The following shall apply to the reporting system:

(1) HIV cases shall not be reported by name.

(2) Data from case surveillance shall only be used to conduct epidemiological analysis, target and evaluate HIV prevention activities, assist in allocation of resources, and plan for future service needs.

(3) Individual case reports shall not be used for contact tracing or partner notification programs.

(d) The HIV Surveillance Task Force shall consist of 12 members appointed by the Director of Health Services. The members of the task force shall select the chair. The department shall provide staff for the task force. The membership of the task force shall be, to the extent possible, drawn from sources outside the department to reflect community-oriented concerns. The membership of the task force shall be as follows:

(1) The chair, or his or her designee, of the state Title II Ryan White CARE working group.

(2) The chair, or his or her designee, of the state Prevention working group.

(3) One additional member of the state Title II Ryan White CARE working group who is infected with HIV or represents a community at high risk for HIV.

(4) One additional member of the state Prevention working group who is infected with HIV or represents a community at high risk for HIV.

(5) An individual with technical expertise in designing systems for health care or social service reporting.

(6) A physician in private practice who treats significant numbers of patients with HIV.

(7) A representative of a laboratory that conducts significant numbers of HIV antibody tests.

(8) A representative with public policy expertise in HIV surveillance from a community-based acquired immune deficiency syndrome (AIDS) service organization.

(9) An academic researcher with expertise in HIV surveillance.

(10) An epidemiologist.

(11) A local health officer.

(12) The Director of the Office of AIDS, or his or her designee, who shall be an ex officio member of the task force.

(e) (1) The uniform, statewide HIV surveillance reporting system developed by the HIV Surveillance Task Force pursuant to this section shall reflect a

sensitivity to the public health implications raised by the avoidance of testing by individuals and shall carefully guard against breaches of confidentiality.

(2) The task force shall not develop an HIV surveillance reporting system that relies on the reporting of the names of HIV infected individuals, nor shall it consider the relative merit of such a system.

(f) The HIV Surveillance Task Force may seek outside expertise from sources including, but not limited to, the University of California, to provide technical assistance in the development of unique code or other nonname based reporting systems.

(g) The HIV Surveillance Task Force shall make recommendations for educating health care providers, local health departments, laboratories, and members of affected communities to promote voluntary compliance with and effectiveness of the system.

(h) The HIV Surveillance Task Force shall examine and recommend additional utilization of noncase reporting surveillance methods including, but not limited to, population-based seroprevalence studies, sentinel and random serosurveys, and behavioral surveillance studies to improve the state's surveillance of the HIV epidemic.

(i) The HIV Surveillance Task Force shall recommend regulatory changes required to implement the HIV reporting system. The State Department of Health Services shall develop and implement regulations based on the recommendations of the task force.

(j) The HIV Surveillance Task Force shall make recommendations regarding the distribution of surveillance information to ensure that the data is available, accessible, and delivered promptly to local consortia and other community planning bodies.

(k) The HIV Surveillance Task Force shall develop criteria by which the HIV surveillance reporting system will be evaluated. The criteria shall include, but not be limited to, the impact of case-based surveillance on the willingness of individuals to seek testing and treatment for HIV. On or before January 1, 2003, the department shall commission an evaluation of the department's

implementation of the HIV surveillance reporting system developed by the HIV Surveillance Task Force using criteria developed by the task force. This subdivision shall not limit interim evaluations. It is the intent of the Legislature that the department continuously assess the effectiveness of the HIV surveillance reporting system.

(l) (1) Nothing in this section shall prohibit or limit the existence of alternative testing sites that provide anonymous HIV testing.

(2) Anonymous test results shall not be reported by the HIV surveillance reporting system authorized by this section.

(m) Nothing in this section shall require the reporting of the results of HIV tests performed on a blood, tissue, or bodily fluid sample provided by an individual to an HIV home collection or home test kit.

~~and Safety Code, to read:~~

~~121040. (a) The department shall conduct a study to determine the most effective method of conducting public health reporting of HIV test results by unique identifier method without the use of names.~~

~~(b) The study shall evaluate all of the following:~~

~~(1) The use of HIV test result reporting by unique identifier methods in other states.~~

~~(2) Other coded systems that are used to protect patient confidentiality.~~

~~(3) The recommendations of groups representing the diverse populations affected by the HIV epidemic.~~

~~(4) Research from the AIDS program of the University of California.~~

~~(5) Other methods to preserve patient confidentiality and promote voluntary HIV testing among affected populations.~~

~~(c) The department shall report the results of the study to the Legislature on or before March 1, 1999.~~

O

B. Thomas Henderson
4106 Bradwood Road
Austin, Texas 78722

February 24, 1998

The Honorable William J. Clinton
President of the United States
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Dear Mr. President:

I am writing to urge your rejection of any recommendation to report HIV infection by using the names of infected individuals. The potential for abuse of such information at the federal, state and local levels is enormous.

The need for improved surveillance of HIV infection is clear. The goals of collecting meaningful, accurate and current data on the prevalence and incidence of HIV infection and connecting as many HIV+ people as possible into care systems are consensus objectives on which almost all of us affected by the AIDS epidemic can agree. However, after a great deal of research and careful thought, I have yet to be convinced that the reporting of cases of HIV infection using the names of those infected accomplishes those goals in a more effective manner than a less intrusive system such as the use of unique identifiers.

Fear of discrimination against those with HIV disease is very real. Although passage of the Americans with Disabilities Act (ADA) was hailed as a hallmark in the protection of individuals living with HIV/AIDS, recent court decisions have cast considerable doubt on its application to those with asymptomatic HIV. Given this country's history of racial discrimination in the guise of public health initiatives, minority communities often distrust public health programs perceived as coercive.

And present assurances of confidentiality cannot prevent later evisceration of privacy guarantees. Once public health officials have compiled a list of individuals who are HIV+, whether at the national, state or even local level, there is no way to safeguard such a list from future overzealous "public health" efforts or misguided political mischief. Just as a legislature may enact confidentiality provisions, so too may it later create exceptions or revoke protections *en toto*.

I would urge in the strongest possible terms that the Department of Health and Human Services and the Centers for Disease Control work to develop an effective HIV surveillance system using tools such as unique identifiers, blinded seroprevalance studies, mathematical modeling techniques, sentinel and random serosurveys, enhanced behavioral research and surveillance activities and other, similar, innovative methods, to ensure the privacy of and to reduce the potential discriminatory impacts on individuals and communities at risk for HIV infection. The rush to HIV names reporting is unwarranted and, I believe, ultimately counterproductive.

Sincerely,

B. Thomas Henderson
Member, President's Advisory Council on HIV/AIDS

cc: Sandra Thurman
Paul Begala
Virginia M. Apuzzo
Richard Socarides

BTH/slm

HIV NAME-BASED SURVEILLANCE FACT SHEET (June 19, 1998)

Purpose of HIV Surveillance: HIV surveillance can be used to provide a minimum estimate of persons living with HIV (HIV prevalence), to identify emerging trends and patterns of infection, to characterize persons more recently infected than those with AIDS, and to evaluate prevention interventions. Demographics and risk behavior information are collected routinely as a part of surveillance. Recently, the occurrence of new cases (incidence) of AIDS and deaths from AIDS have declined because of effective medical treatment. This is not likely to be representative of the trends in the incidence or prevalence of HIV and is likely to be an underestimate of disease.

States That Have HIV Surveillance: 28 states have name-based HIV reporting for adults and children, 3 states have name-based reporting for children under 13 years old, and one state has name-based reporting for persons with symptomatic HIV infection. 13 states and the Virgin Islands have non-name-based reporting and 10 states, Puerto Rico, and the District of Columbia do not have HIV surveillance. Several state legislatures have either passed laws or are considering legislation regarding HIV surveillance; therefore, these numbers are likely to change in the near future.

Purpose of Collecting Names: Names allow health department personnel to most efficiently follow-up cases through review of existing records for complete collection of demographic and risk information as well as elimination of duplicate reports of the same person. This ensures a representative and reliable surveillance system. HIV name-based surveillance is already conducted in 31 states. New or multiple systems would be costly in development, infrastructure, and additional personnel. No names are reported to CDC.

Security of Names in HIV Surveillance: Confidentiality of a state AIDS reporting system has been breached only once since 1981 and no names were released publicly. There have been no known breaches associated with the adoption of name-based HIV surveillance.

Problems with an "Unique Identifier" as an Alternative to a Name: Unique identifiers (a number that is not duplicated and cannot by itself be translated into identifying information) are not anonymous because they can be linked at some stage to a name. A sufficiently unique and cryptic identifier is difficult to construct. Multiple lists outside of the health department's control and without sufficient confidentiality safeguards must exist in a system that depends on unique identifiers, creating a system that has less guarantee of confidentiality.

Surveillance Is a Minor Deterrent to Testing and Care: CDC, in collaboration with the University of California at San Francisco and state health departments, evaluated the effect of HIV surveillance on test-seeking behavior and found 0.5-2.0% of persons delay testing or seeking medical care principally because of concern that if infected their names would be reported. In states that have recently instituted HIV name-based reporting, there were no significant declines in the number of HIV tests provided by publicly funded counseling and

testing sites in the months immediately after implementation of the reporting policies, other than the declines expected from trends that were present before HIV reporting.

Availability of Anonymous Testing Is Not Incompatible with Name-based Surveillance: The availability of anonymous services may encourage some persons at risk for HIV infection to seek HIV prevention services that they may otherwise be reluctant to seek. CDC requires that states receiving prevention funds make anonymous testing available unless prohibited by state law. Maintaining an anonymous testing option may help ensure that more people learn their status and if infected, seek early treatment and care.

Surveillance Is Not a Substitute for Other Targeted Studies: CDC strives to provide a comprehensive picture of the HIV epidemic by analysis of data collected through HIV and AIDS surveillance, mortality data, blinded seroprevalence studies, surveillance for antiretroviral drug resistance, behavioral surveillance, and data collected through studies designed to answer specific questions. A variety of techniques, including new laboratory technology, are used in these surveillance systems and studies.

Referrals for Care and Partner Notification Are Independent of Surveillance: The referral of an HIV-infected client for care and eliciting information for partner notification are both activities that are independent of HIV surveillance. They are both based on the voluntary cooperation of the HIV-infected client and do not require HIV surveillance -- name-based or otherwise -- to function well. Conversely, HIV name-based surveillance will not interfere with these activities.

Surveillance must Have a High Level of Completeness: CDC has established performance criteria for HIV and AIDS surveillance to ensure that surveillance data are of sufficient quality to target prevention and care resources and to detect emerging trends in the HIV epidemic. CDC estimates that 85% completeness will be required of HIV surveillance to allow appropriate analyses. Less complete reporting would allow significant opportunity for differences in reporting among groups; those differences would make comparisons among groups problematic.

Modeling Is Not a Substitute for Surveillance: Statistical models have been used successfully to reconstruct the pattern of HIV incidence in the U.S. population; this is not surveillance, however, and the data to allow meaningful modeling are scarce (e.g., no population seroprevalence data available since 1994). Mathematical modeling is not useful for predicting the future of the epidemic or estimating the current prevalence and incidence of HIV. This poor ability to predict the epidemic is revealed when different mathematical models that fit historical epidemiologic data equally well have very different projections for the short or the longer term.

- **Reference of HIV surveillance as an "extension" of AIDS surveillance**: The constant attempt to link HIV and AIDS surveillance predisposes/presumes the use of names; this is essentially a euphemism for names reporting

- **Referrals to medical care**: Several times in the guidance, referrals and/or linkages to medical care are discussed; although we support enhanced referrals and linkages to medical care, this is not the goal of surveillance and should not be linked in this manner; SF and CA do a great job of linking people to care without HIV surveillance; although the guidance never directly links surveillance with referrals to medical care it seems to be implied; references to linkage to care can be found on pages 3, 18, and 26-27

- **Unique identifier states**: Maryland and Texas are completely excluded from the list of states that conduct HIV surveillance in guidance and the MMWR (page 4); this seems to imply that these states provide no data at all which is not true

- **Community concerns are not addressed**: The document does not articulate the concerns of the community, particularly the likely *deterrence to testing and/or treatment* that can occur as a result of names-based reporting; these concerns are glossed over at best

- **Studies on deterrence to testing**: The interpretation of the data from MESH studies (page 7) is problematic—the fact that 18% indicated NR as a factor is—and should be—troubling; the fact that people don't know about their state's policies is an unacceptable rationale; people should have informed consent before testing is conducted

- **Unique identifier critique**: This section of the document (pages 7-8) does not acknowledge several important facts—(1) no funds were provided to the states that conducted UI reporting, (2) the CDC provided no expertise assistance in developing these systems; (3) data has improved over time in MD, and (4) Texas Health Department was not committed to developing a workable system

- **Provider log issue**: Provider lists would be smaller (not a statewide list) and would not be subject to legislative misuse; laws regarding disclosure should be strengthened and more strictly enforced to reduce potential breeches if logs are kept; there are ways for providers to keep logs without having lists of names (using medical record numbers, etc.)

- **Model confidentiality language for states**: If model confidentiality language (referred to on pages 9 and 24) is so important why isn't it being released simultaneously with the CDC's guidance?

- **Notion that there have been "few breeches"**: This statement on page 9 seems to completely ignore and dismiss anecdotal evidence about numerous breeches as

well as the Florida situation altogether; also does not recognize the potential for legislative misuse in an increasingly hostile political environment

- **Performance criteria (page 12)**: Where did these standards come from? Are they used to evaluate other surveillance systems? If these are in fact standard guidelines (which we doubt), the public health consequences of HIV names reporting justify loosening the criteria (e.g. lowering completeness to 70%); standards should not be set unnecessarily high—we can get good trend analysis without 100% accurate data

- **CDC's recommendation for names reporting (pages 13 and 23)**: The CDC should not recommend how state's should implement HIV surveillance; this is antithetical to state and local control; CDC should simply lay out criteria and provide equal support to state's moving towards names reporting and those who are opting for a non-names based system

- **Evaluation date (page 13)**: One year is too short for systems to meet the performance criteria; this should be extended to three years

- **De-linkage from partner notification (pages 18 and 27)**: CDC does not adequately urge state's to de-link PN and surveillance; CDC is reneging on its responsibility to de-link the two

- **Collecting data vs. encouraging testing and treatment**: It is surprising that the CDC's efforts to collect data seem to receive greater importance than the vital public health functions of preventing HIV infections, getting people tested and into treatment; names reporting is not necessary to get people tested and linked to treatment—these are the goals that HHS, CDC and the community share and should be pursued with even greater vigor than the attempt to collect better data

- **Jeopardize relationship with HIV community**: Why jeopardize an already fragile relationship with the community when there may be a possible solution (allowing state's to develop systems they believe are more appropriate)? The United States must balance accuracy of data with very real public health concerns of the community

- **HIPAA UI (page 23)**: Congress/HHS is potentially working on a UI for medical records generally which could make entire issue moot; furthermore, how can CDC suggest that UIs are impossible when there are currently attempts being made to develop such a system for the country as a whole?

- **Routine collection of data from managed care organizations (page 22)**: The recommendation of the CDC on page 22 that health departments routinely collect data from MCOs is extremely alarming and problematic.

- **Listing of groups that support names reporting**: On page 23, several groups that support NR are listed but there is no reference to the numerous groups that oppose this type of system (ACLU, AAC, NAPWA, etc.). Why this imbalance?

- **Guidance should be limited to factual information and should limit unnecessary interpretation/commentary**

- **We can actually get very good data without reporting**: Other ways to get good data (seroprevalence studies, population-based sampling, etc.) are all but ignored in the CDC guidance; San Francisco has some of the best data in the country *without* any HIV case reporting

- **States should not experience any penalties for developing alternative reporting systems**: CDC should support innovative ways for dealing with this issue that are developed by states; as it is currently written, the guidance would greatly reduce the ability of state's to develop systems that would decrease the negative public health impact; CDC should not hamper this process in any way.

- **Inappropriate referencing of non-CDC organizations in a technical guidance.** Throughout the length of the draft guidance, CDC references (often inappropriately) organizations who are not part of the Public Health Service to bolster their position in support (tacitly and often overtly) for name reporting.

- **Draft guidance is overly proscriptive and does not encourage or allow for state flexibility in the implementation of a change in Public Health Service policy.**

- **Draft guidance alleges community input in March 1998, although there has yet to be a community review of this draft Guidance.** To characterize the March 1998 meeting as a review of this draft guidance would not only be inaccurate, but a mischaracterization of even the informal CDC presentation at this meting.

- **CDC mischaracterizes it assistance to jurisdictions regarding expanding AIDS case surveillance to include HIV surveillance.** CDC provided technical assistance (and financial resource) to states to expand their AIDS surveillance to incorporate HIV infection reporting by name (CF. Pages 4 and 6 and 7); however, only evaluated the Unique Identifier experiences in Maryland and Texas.

- **CDC mischaracterizes community concerns with HIV infection reporting by name.** There is a tremendous consensus among the HIV community to expand surveillance to include HIV infection. However, page 4 of the draft guidance, CDC confuses (intentionally) HIV surveillance with HIV infection case reporting by name as being identical. HIV surveillance can be done through a variety of methods – this guidance clearly contends that disagreement with name reporting is the same as disagreeing with HIV surveillance, which is not the case.

- **Draft guidance mischaracterizes ~~meaning~~ value of data of HIV infection case reporting** (page 4). HIV infection case reporting is a measure of the extent of the epidemic among those individuals and communities that seek HIV testing. This is the limitation of HIV surveillance. HIV infection case reporting, by its very nature, offers not a true account of a jurisdiction's HIV cases, only a true account of those who sought out testing.

- **The scientific citations justifying the utility of HIV surveillance and its impact on prevention programs are poor**. A personal communication between an individual and the CDC is neither statistically significant nor quantifiable (Cf. page 5). There are 28 states with this process in place, but apart from flimsy examples of New Jersey PROCESS OUTCOMES and similar, truncated examples from Minnesota and Michigan, the document lacks quantifiable examples of using HIV infection case reporting by name to signal a resource re-allocation of evaluation of HIV prevention investments. For each of the three name-based states cited as examples, there are an equal (if not greater) number of states who have done similar processes without HIV name reporting.

- **The draft guidance selectively chooses data sets from the HITS and APS studies while omitting data that would contradict the assertions of this guidance**. For example, APS data show that individuals in name-based states report a lower initial CD4+ count than do those in non-name states (data with statistical significance). Additionally, the draft guidance ignores the preeminence of data indicating the impact of stigma on test-seeking behavior. Further, the draft guidance suggests that a survey with 2,730 respondents across nine states constitutes a national, representative sample and that this sample has sufficient power to indicate national trends.

- **The dismissal of Unique Identifiers (page 8) ignores the contention of Maryland.**

- **The guidance consistently rationalizes the expansion of surveillance to include HIV infection case reporting based upon the APPLICATION OF DATA, not upon the function of COLLECTING TIMELY AND ACCURATE DATA**. Specifically, the entire document justifies expansion to HIV surveillance because of access to care and access to HIV therapies. However, by its own admission, the goal of HIV and AIDS surveillance is "the collection of accurate and timely epidemiologic data" (page 18). Yet, the guidance states that the expansion is necessary for purposes of access to care and the evaluation of such access. Additionally, the document never scientifically justifies the rationale behind the three performance indicators (for completeness, timeliness and duplication). No where is there a justification for these percentages, their relative importance and their implementation.

- **Using Medicaid to evaluate the HIV surveillance system is unreasonable**. HCSUS data demonstrates that well over 50% of all Americans with HIV disease do not have any access to medical care. Justifying HIV surveillance by evaluating this system using the Medicaid roll will neither show true access to care as an outcome of surveillance (which again is not surveillance's function) nor demonstrates a system accurately tracking individuals with HIV disease.

- **Evaluating the new surveillance system after one year is a set-up for failure for not only UI states, but those states already implementing HIV reporting by name**. CDC's own data (page 22) show that several name-reporting states have a completeness rate of only 79%. This clearly is below the minimum percentage established by this guidance.

- **CDC suggests NO REPARATIVE ASISTANCE to any jurisdiction not meeting any or all of the three performance criteria**.

- **CDC has reneged on it commitment to decouple HIV surveillance from other programs such as Partner Notification**. Publicly, CDC has stated to the community that this guidance would clearly decouple HIV surveillance from Partner Notification. However, the draft guidance does not state this as a CDC policy and

alludes, in passing , to concurrence from a community planning group NOT TO THE LINKING OR DELINKING, but to an overall sense of resonance (see page 18). Later in the document, CDC OMITS any reference of CPG concurrence in light of Partner Notification programs, thereby establishing a conflicting message within the guidance and therefore to the jurisdictions (see page 27).

- **State protections for privacy and confidentiality are suggested but not required.** States can implement HIV surveillance by name with absolutely no requirement from CDC as to the minimum level of legal protection within the state.

- **CDC carefully omits the fact that 10 states have eliminated anonymous testing since expanding their AIDS surveillance to include HIV reporting by name.**

- **CDC ignores its own data (April 28, 1998 MMWR) when it falsely states that HIV surveillance will give an accurate and timely profile of a jurisdiction's HIV rate.** In the 4/28/98 MMWR, 28% of the cases had UNREPORTED RISK, meaning that the alleged data showing risk and other demographic information was not available at the time of the submission of this data to CDC. Data with no reported risk neither facilitates good planning nor a serious analysis of gaps in services (prevention or otherwise).

Bill to Track People Infected With H.I.V. Gains in Albany

By RICHARD PÉREZ-PEÑA

ALBANY, June 18 — With just hours left in the legislative session, leaders of the State Assembly tonight dropped their opposition to a measure requiring that the names of H.I.V.-positive people be reported to the state and mandating that government health workers ask infected people to name their sexual partners so they can be notified that they are at risk.

The Republican-controlled Senate passed the bill tonight by a vote of 55 to 6, and a large majority of Assembly members is known to favor the measure, which has been kept from a vote by the leadership in recent years. Gov. George E. Pataki, a Republican, also favors the bill in concept, but aides said he would not comment on it until his lawyers had read it.

After years of resisting the concept, the Democrats who control the Assembly said their house would pass the bill requiring reporting, by name, of people infected with the AIDS virus, to the State Health Department, which would keep a central registry of the names of infected people.

Local health agencies would be required to interview all people reported as testing positive, ask them to name their sexual partners, and then warn those partners that they had been exposed to the virus. But the law would not penalize anyone who refused to divulge the names of their sexual partners.

Twenty-eight other states, including New Jersey, already track H.I.V. cases by name, but many of those do not mandate the tracing of contacts. Passage of the measure in New York would be significant because it has the nation's highest rate of reported AIDS cases.

Public health officials have said that reporting by name and tracing contacts are needed to make sure that people are aware that they have been exposed to the virus, in part to reduce the risk of spreading the infection.

AIDS-treatment advocacy groups have fought the measure, contending that it would discourage people from being tested and seeking treatment. Some said patients could be effectively tracked without using their names, by assigning them identification codes. But supporters of the bill said such a system would be cumbersome and might hinder the ability to track the spread of the disease.

It has long been clear that such a bill had enough votes to pass the Assembly — nearly all the 53 Republicans and most of the 97 Democrats favor it — but Assembly Speaker Sheldon Silver kept it from coming to a vote for years.

The bill's sponsor, Assemblywoman Nettie Mayersohn, a Queens Democrat, has been a loud and relentless advocate, spending years trying to embarrass Mr. Silver into allowing a vote. And many Assembly members have said the public pressure on them to act grew greatly with the news last fall that one man, Nushawn J. Williams, had infected more than a dozen women and girls in small towns in western New York.

On the last day of the legislative session, Mr. Silver gave in to pressure from other Democrats. Many genuinely supported the measure, while others feared their failure to act on it would be used against them as a campaign issue by Republicans. Mr. Silver negotiated some minor changes with Ms. Mayersohn, then freed legislators to vote as they pleased. The bill squeaked through two committees, by votes of 11 to 10, before going to the floor.

"This is a great moment for common sense," said Ms. Mayersohn. "This is what we do with every other serious communicable disease, and what we should have done years ago with this one."

Fear that a measure will dissuade some from seeking help.

But Robert Jaffe, a lobbyist for Gay Men's Health Crisis, said, "It really intrudes upon the relationship between the physician and the patient. The idea that H.I.V.-positive persons will disclose to government workers who they don't know and don't trust is a fantasy. From the beginning, we've been told this was being driven by the politics surrounding the Nushawn Williams case."

Despite the resolution of the AIDS issue, many legislators expressed disappointment about a session that seemed much more promising months ago. In April, many lawmakers were euphoric after the Legislature enacted the least-tardy state budget in five years. For the first time, the budget was hammered out in conference committees, with the involvement of many rank-and-file legislators, rather than in secret meetings among state leaders.

But for those same lawmakers, the last seven weeks of the session — and the final 48 hours in particular — were a distinct letdown. Mr. Pataki, who is running for re-election, took much of the wind out of the Legislature's sails by vetoing $1.6 billion in spending it had approved, and the rest of the session sank into a morass of recriminations and election-year politicking.

"Outside of getting a budget done in a timely way, there was virtually nothing accomplished here," said Assemblyman John J. Faso of Kinderhook, the Republican minority leader. "It's been a very frustrating session."

One of the final deals made by lawmakers strikes at health insurers that deny people coverage for treatment, whose only option is to appeal the insurer. Instead, the agreement reached by Mr. Silver, Mr. Pataki and the Senate majority leader, Joseph L. Bruno, would allow patients to appeal a denial of treatment — including of experimental treatments — to an independent arbiter chosen by the State Health Department. Both houses were expected to approve the bill tonight.

The bill could neutralize what was shaping up to be an issue in the gubernatorial race. Lieut. Gov. Betsy McCaughey Ross, Mr. Pataki's one-time protégée who is now running against him as a Democrat, has made attacks on health maintenance organizations and calls for an outside appeals process a centerpiece of her campaign, and some of the other Democrats in the race have joined in.

Mr. Silver, Mr. Pataki and Mr. Bruno also agreed on an expansion of the state's health care program for children of low-income families, which will be paid for by New York's share of a $24 billion Federal grant program established last year. About 420,000 children are eligible for the program, but fewer than half that number are enrolled.

The most prominent proposal to fade away in the waning hours, and the one Mr. Pataki had pressed for most vigorously, was one that would have ended parole boards' ability to release violent felons from prison early. Under the measure, felons would have been required to serve at least 85 percent of their sentences.

As with many of the issues taken up this year, the Democratic Assembly leaders were reluctant to go along, but were aware that the Governor's position was popular, and that Democrats might pay a price at the polls for opposing it.

In the second-to-last week of the session, Mr. Silver said he would accept the parole provision if it were linked to expanded education programs in prisons and to laws allowing some felons to be sentenced to drug treatment programs rather than prison. Mr. Pataki and Mr. Bruno rejected those conditions, and despite negotiations that continued far into the night tonight, no compromise was reached.

NOTICE OF PUBLIC HEARING ON PROPOSED PROJECT AND ISSUANCE OF REVENUE BONDS BY THE DORMITORY AUTHORITY OF THE STATE

NOTICE OF PUBLIC HEARING ON PROPOSED PROJECT AND ISSUANCE OF FHA-INSURED MORTGAGE HOSPITAL REVENUE BONDS BY THE DORMITORY AUTHORITY OF THE

STATE OF MARYLAND
OFFICE OF THE GOVERNOR

PARRIS N. GLENDENING
GOVERNOR

ANNAPOLIS OFFICE
STATE HOUSE
100 STATE CIRCLE
ANNAPOLIS, MARYLAND 21401
(410) 974-3901

WASHINGTON OFFICE
SUITE 311
444 NORTH CAPITOL STREET, N.W.
WASHINGTON, D.C. 20001
(202) 624-1430

TDD (410) 333-3098

June 1, 1998

The Honorable William J. Clinton
President
The White House
Washington DC 20500

Dear Mr. President:

The Center for Disease Control's (CDC) plan to issue guidelines recommending that all states adopt a name-based HIV surveillance system concerns me greatly. While I fully support the development of HIV surveillance systems to more accurately track the scope of the HIV epidemic, the CDC should not attempt to limit states by implementing only name-based systems. As Governor of a State whose law requires a non-name based surveillance system, I request that CDC promote a more balanced approach.

In the past three years, Maryland has implemented a non-name based surveillance system. This was done in response to legislation considered and passed by the Maryland state legislature (Health General §18-205, Laboratory Examination Reports). Our Health Department has worked to implement, evaluate and improve our system. The current HIV surveillance system, by unique identifier, has provided the Department of Health and Mental Hygiene with sufficient information to effectively conduct disease surveillance, identify new demographic trends, and appropriately target prevention efforts and limited health resources. Maryland has implemented its system without financial support from the CDC although the Department has requested to use funds from Maryland's surveillance cooperative agreement, including unspent funds.

Maryland and other State public health officials should be allowed to choose an HIV surveillance system based on the needs of our communities. State self-determination has long been the hallmark of our nation's public health efforts and disease surveillance strategies, and has been traditionally supported by the CDC. I request that any CDC guidelines offer support and flexibility to develop HIV surveillance systems with specific outcome objectives,

State of Maryland

DEPARTMENT OF HEALTH & MENTAL HYGIENE
AIDS ADMINISTRATION

500 N. Calvert Street, 5th Fl.
Baltimore, Maryland 21202

Liza Solomon, M.H.S., Dr.P.H.
Director
AIDS Administration

(410) 767-5013 FAX (410) 333-6333

whether employing name or non-name based systems, in keeping with State self-determination and autonomy. Federal resources should be distributed in support of a range of state-determined surveillance systems that can reach a set of prescribed objectives.

Thank you for your attention to this very important matter. If you have any questions, please feel free to contact me, or have your staff contact my Washington, D.C. office at (202) 624-1430.

Sincerely,

Parris N. Glendening

Parris N. Glendening
Governor

STATE OF MARYLAND
OFFICE OF THE GOVERNOR

PARRIS N. GLENDENING
GOVERNOR

ANNAPOLIS OFFICE
STATE HOUSE
100 STATE CIRCLE
ANNAPOLIS, MARYLAND 21401
(410) 974-3901

WASHINGTON OFFICE
SUITE 311
444 NORTH CAPITOL STREET, N.W.
WASHINGTON, D.C. 20001
(202) 624-1430

TDD (410) 333-3098

June 1, 1998

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Room 615 F
Washington, DC 20201

Dear Secretary Shalala:

The Center for Disease Control's (CDC) plan to issue guidelines recommending that all states adopt a name-based HIV surveillance system concerns me greatly. While I fully support the development of HIV surveillance systems to more accurately track the scope of the HIV epidemic, the CDC should not attempt to limit states by implementing only name-based systems. As Governor of a State whose law requires a non-name based surveillance system, I request that CDC promote a more balanced approach.

In the past three years, Maryland has implemented a non-name based surveillance system. This was done in response to legislation considered and passed by the Maryland state legislature (Health General §18-205, Laboratory Examination Reports). Our Health Department has worked to implement, evaluate and improve our system. The current HIV surveillance system, by unique identifier, has provided the Department of Health and Mental Hygiene with sufficient information to effectively conduct disease surveillance, identify new demographic trends, and appropriately target prevention efforts and limited health resources. Maryland has implemented its system without financial support from the CDC although the Department has requested to use funds from Maryland's surveillance cooperative agreement, including unspent funds.

Maryland and other State public health officials should be allowed to choose an HIV surveillance system based on the needs of our communities. State self-determination has long been the hallmark of our nation's public health efforts and disease surveillance strategies, and has been traditionally supported by the CDC. I request that any CDC guidelines offer support and flexibility to develop HIV surveillance systems with specific outcome objectives,

whether employing name or non-name based systems, in keeping with State self-determination and autonomy. Federal resources should be distributed in support of a range of state-determined surveillance systems that can reach a set of prescribed objectives.

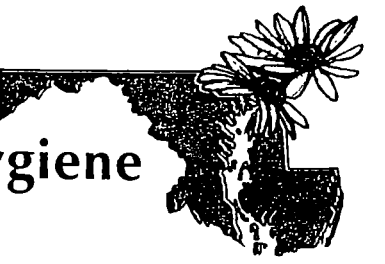
Thank you for your attention to this very important matter. If you have any questions, please feel free to contact me, or have your staff contact my Washington, D.C. office at (202) 624-1430.

Sincerely,

Parris N. Glendening

Parris N. Glendening
Governor

State of Maryland
Department of Health and Mental Hygiene
Parris N. Glendening, Governor - Martin P. Wasserman, M.D., J.D., Secretary



APR 0 7 1998

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Room 615F
Washington DC 20201

Dear Secretary Shalala:

We are writing to express our concern about the Center for Disease Control's (CDC) plan to issue guidelines recommending that all states adopt a name-based HIV surveillance system. While we fully support the development of HIV surveillance systems to more accurately track the scope of the HIV epidemic, we feel that the CDC should not attempt to limit states by implementing only name-based systems. As the public health official of a state whose law requires a non-name based surveillance system, I would like to respectfully request that CDC promote a more balanced approach.

In the past three years, Maryland has implemented a non-name based surveillance system. This was done in response to legislation considered and passed by the Maryland State Legislature (Health General §18-205 Laboratory Examination Reports). Our Health Department has worked to implement, evaluate and improve our system. Although recently questioned by the CDC (MMWR Vol. 46, January 9, 1998), we believe that our current HIV surveillance system, by unique identifier, has provided our Department with sufficient information to effectively conduct disease surveillance, identify new demographic trends, and appropriately target prevention efforts and limited health resources. We have been able to implement our system without financial support from the CDC although we have requested to use funds from Maryland's surveillance cooperative agreement, including unspent funds.

Maryland and other state public health officials should be allowed to choose an HIV surveillance system based on the needs of their individual communities. State self-determination has long been the hallmark of our nation's public health efforts and disease surveillance strategies, and has been traditionally and consistently supported by the CDC. Specifically, we request that any CDC guidelines offer support and flexibility to the states to develop HIV

surveillance systems with specific outcome objectives, whether employing name or non-name based systems, in keeping with State self-determination and autonomy. Federal resources should be distributed in support of a range of state-determined surveillance systems that can reach a set of prescribed objectives.

Thank you for your attention to this very important matter.

Sincerely,

Martin P. Wasserman, M.D., J.D.
Secretary

State of Maryland

AIDS ADMINISTRATION
DEPARTMENT OF HEALTH AND MENTAL HYGIENE
500 NORTH CALVERT STREET • BALTIMORE, MARYLAND 21202 • (410) 767- 5013

Martin P. Wasserman, M.D., J.D.
Secretary

Liza Solomon, M.H.S., Dr.P.H.
Director

HIV Surveillance by non-name based identifier, the Maryland Experience

In order to enhance our understanding of the full spectrum of HIV disease and to better understand the epidemiology of those newly infected with HIV, Maryland implemented a system of HIV surveillance. Beginning in 1994 Maryland began HIV reporting using non-name based unique identifier (UI) codes. This report describes the Maryland system, how it works, and presents some initial findings from the Maryland evaluation.

Why non named based HIV surveillance?

Maryland's UI system was implemented after attempts to institute HIV name reporting were defeated in the Maryland legislature over the course of many years (bills defeated yearly 1988-1994). An important consideration in the defeat of a name based surveillance system was concern that such a system would discourage individuals from seeking HIV testing and thus delay treatment. The decision to move forward with a UI based HIV surveillance system was strongly supported by the HIV affected community in Maryland.

Description of the Program

The Maryland HIV surveillance program requires that positive HIV tests and CD 4 counts of 200 or less are reported by laboratories using a unique identifier (UI). Exemptions to the UI reporting system include blood, semen or tissue donors, individuals who do not reside in Maryland, DHMH designated anonymous test sites, and some limited research activities.

The UI is a 12 digit number consisting of the last four digits of the social security number (SSN), the individual's date of birth, a digit representing the individual's race/ethnicity and a digit for the individual's gender. The provider who orders an HIV or CD4 test creates the UI number which is sent with the laboratory requisition. The laboratory sends the UI report form for positive HIV tests and CD4 counts less than 200 to the state AIDS Administration office or to the local health department, which then forwards the report to the AIDS Administration. The AIDS Administration matches each UI received against the State AIDS Registry, (UIs were created for all records in the AIDS registry) thus creating a registry of HIV infection that is not yet reportable as AIDS. Surveillance staff

call physicians as necessary to verify the UI number, check for incomplete information, and obtain information on clinical status and risk categories. Patient names are not given to the surveillance staff unless the clinician indicates that the patient has been diagnosed with an AIDS defining condition. Surveillance staff may then assist the clinician in filling out an AIDS case report.

Implementation of the UI system

In order to get an unduplicated count of the number of individuals with HIV infection, and to be able to differentiate between newly diagnosed HIV cases from previously reported AIDS cases, it is important to have the UI code filled in accurately and completely. An evaluation of the completeness of UI elements reveals that there has been significant improvement in the completeness of UI elements over time, as providers have become more used to the UI system. While only 55% of the UIs were complete in the first six months of the program, 66% percent of UIs reported in the last six months of 1997 were complete. In an assessment of our ability to improve on the completeness of UI numbers, additional training was provided to staff at Counseling and Testing Sites; after the initial training period, completeness of UI numbers increased to 97 percent. This suggests that continued provider education and assistance would improve on the overall completeness of UIs.

Ongoing evaluation of the UI system - does it work?

As implementation of the UI system continues, several evaluation activities are underway. In addition to the ongoing assessment of the completeness of the UI number, the AIDS Administration has conducted an evaluation of the "uniqueness" of the UI. This analysis included two approaches, an examination of whether UIs could effectively differentiate separate individuals, and an assessment of the completeness of reporting.

To test the uniqueness of the UI we examined the records from Maryland residents in the AIDS registry in which we were able to create a full UI number. We then examined how often identical UI's would be found in a registry which should contain no duplicates. Of the 15,672 records in the AIDS registry, use of the full UI was able to correctly differentiate individuals greater than 99% of the time.

To test whether this 99% uniqueness would hold true in the field, the AIDS Administration examined all identical UIs in one jurisdiction. In a comparison of records from clients who had the same UI but had made several visits we were able to demonstrate that individuals were correctly given the same UI when they received additional HIV positive test results or additional CD4 counts. Although this analysis of uniqueness will be performed in other areas of the state to confirm this result, this initial examination suggests that the UI numbers do work to designate unique individuals.

An analysis of the completeness of reporting is currently underway. However, preliminary data demonstrates that completeness of HIV reporting in Maryland is comparable to that

seen in names reporting states. According to the Centers for Disease Control and Prevention, among states that have HIV name based reporting, the ratio of new HIV to new AIDS cases varies from 0.6 (Arizona) to 1.6 (Nebraska) with a mean of 0.9. The ratio of HIV to AIDS cases in Maryland is 0.9, suggesting that the data obtained from Maryland's reporting system is comparable to that seen in name based states.

What we learned from our HIV reporting system - HIV AIDS differences

In order to appropriately plan prevention services and allocate treatment resources to areas of greatest need, both HIV and AIDS cases must be examined. A comparison of age, race and gender characteristics of those diagnosed with HIV with AIDS demonstrated significant differences in age and gender distribution. In 1996, 29 percent of new AIDS cases in Maryland were found among women, however, 41 percent of HIV cases in that year were seen in women. Differences in age distribution of those with HIV as compared to those with AIDS were also seen. Among cases of AIDS reported in 1996 13 percent were among individuals age 20 to 29; however, among individuals with HIV only, 21 percent were within this age group. Also of interest is the finding that the number of individuals above 50 with AIDS is higher than those seen among individuals with HIV. An examination of race differences did not show any significant change in patterns among those with HIV infection versus AIDS, 82 percent of those with AIDS are minorities as compared to 82 percent of individuals diagnosed with HIV. Data from our HIV reporting system will be used to guide prevention and services resource allocations.

Conclusion

Maryland's UI system has provided epidemiologic data which will be of increasing importance to our states' ability to understand the changes in the HIV epidemic. The creation and maintenance of the Maryland HIV reporting system has been implemented with minimal cost and without additional federal or state support. We believe that states considering implementing an HIV reporting system may want to consider models such as Maryland's to help provide needed epidemiologic data while protecting the confidentiality of people with HIV.

HOME

PROFILES

GAZETTE

COLUMNS

CULTURE

SURVIVAL

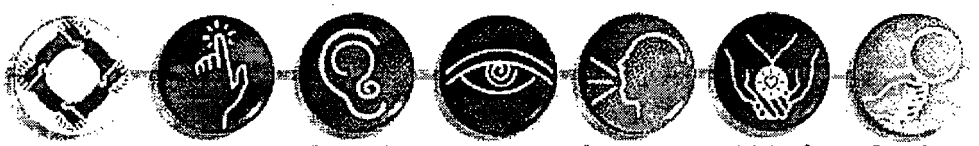
Number's Up

CDC gives thumbs down for unique identifier

Edited by RonniLyn Pustil
by Becky Minnich

Numbers? Names? Neither? The battle over HIV case reporting continued in January when the Centers for Disease Control and Prevention (CDC) published an article criticizing the use of unique identifier (UI) codes for tracking HIV cases by Texas and Maryland, the only two states with such a system. The codes, which include birthdates and partial Social Security numbers, are meant to dispel would-be test-takers' fear that their names will be sent to a state agency. Most AIDS organizations favor UIs over names, and some reject any form of listmaking as a recipe for driving those at risk underground. But the CDC is pushing for names, claiming that UIs "complicate efforts to collect risk-behavior information" and "contribute to a high rate of incomplete case reporting." Officials in charge of Maryland's three-year-old UI system admit flaws but remain fans. "We're seeing improvement in completion of codes," said Liza Solomon, director of AIDS administration for Maryland's Department of Health, adding: "If you really want a system to work, it needs to be supported. The CDC refuses to fund UI systems."

Previous article | Next article | Back to *POZ* May 1998 contents page



NATIONAL INSTITUTES OF HEALTH
OFFICE OF AIDS RESEARCH

Office of AIDS Research Advisory Council
Building 31, Room 4C02
31 Center Drive
MSC 2340
Bethesda, MD 20892
TEL: 301 496 0357
FAX: 301 496 2119

MAY 14 1998

The Honorable Donna E. Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

As the Chair of the NIH Office of AIDS Research Advisory Council, I am transmitting to you a recommendation that received the unanimous support of the Council at our April 29 meeting.

The Office of AIDS Research Advisory Council expresses great concern that the system for tracking the HIV/AIDS epidemic in the United States may become increasingly inaccurate as a result of the current method of name reporting of HIV infection. The need for accurate and timely data on both AIDS and HIV disease prevalence and incidence remains of central importance for prevention, treatment, and policy planning. However, continuing concern about the potential and real misuse of name reporting of HIV infection will likely result in individuals' and communities' avoidance of the use of prevention and treatment resources. Underreporting and biased reporting will result. This, in turn, will have adverse effects on the nation's response to the continuing threat and consequences of HIV disease and may blunt the great progress that has been made in both prevention and treatment.

The technology exists for coded encryption. The Advisory Council strongly recommends that this technology be applied to an HIV reporting system that would assure both accuracy and completeness of reporting, and the protection of confidentiality.

Sincerely,

Charles C.J. Carpenter

Charles C.J. Carpenter, M.D.
Chair, Office of AIDS Research Advisory Council

cc:
Dr. David Satcher, Surgeon General
Dr. Claire Broome, CDC

AIDS Action council

October 27, 1997

Helene Gayle
Director, Center on HIV/AIDS, STD, and TB Prevention
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333

Dear Dr. Gayle:

AIDS *Action*, representing over 2,000 community-based organizations, is writing to express concern over the Centers for Disease Control and Prevention's (CDC) efforts to modify the nation's current AIDS/HIV surveillance system by moving to a names based system for HIV reporting. AIDS *Action* recently resolved to support HIV reporting by unique identifiers (UI) and other non-names based surveillance systems (see enclosure).

Given our community's long-standing history of working together to resolve difficult issues and implement sound public health policies, we are concerned about the method and speed by which CDC is moving to implement a new HIV names reporting system. **AIDS *Action* urges the CDC to reconsider the rapid implementation of a new HIV surveillance system based on names.** Instead, we propose that the CDC continue to work with community, health, and state advocates in developing a new HIV surveillance system that will gather the data we need to have a more accurate picture of the epidemic.

1875
Connecticut Ave NW
Suite 700
Washington DC
20009
Fax 202 986 1345
Tel 202 986 1300

Although all states conduct AIDS surveillance based on names, the prospect of adopting this system for HIV is significantly different and potentially more devastating. We are deeply concerned that the CDC's new system will not take into consideration a myriad of complex issues such as:

- removing barriers to testing including increasing the availability of anonymous testing;
- confidentiality and privacy concerns;
- linkages to care and new treatments; and
- development of sophisticated non-names based HIV surveillance systems.

These issues are critical to the success of any new HIV surveillance system that is developed. For example, we believe the CDC needs to be more vigilant about encouraging HIV testing, ensuring confidentiality, and removing obstacles that discourage testing. The collection of names on central HIV registries will serve as a serious deterrent to HIV testing, particularly for individuals in high-risk groups. The absence of anonymous testing in a number of states is disturbing and also

serves as a deterrent to individuals seeking testing. **AIDS *Action* recommends that CDC encourage <u>all states</u> to provide anonymous testing to ensure that individuals are not deterred from seeking HIV testing.** Reversing the trend exemplified by the ten states that do not offer anonymous testing, but have HIV names reporting, is essential.

In the area of confidentiality and privacy, it is important to consider that HIV names registries are likely to be kept for 20-30 years instead of the 20-30 months that the registries were kept for individuals with end stage AIDS diagnoses. People with HIV infection are still working, applying for insurance and loans, all of which could be jeopardized by the mishandling of these registries. In light of these circumstances and recent court decisions which suggest that asymptomatic HIV positive individuals may not be afforded discrimination protections under the Americans with Disabilities Act, we have grave concerns about a names based system.

Linkages to care and access to early interventions are essential to help HIV infected individuals stay healthy. However, the proposed new system would do little to help HIV infected populations access our medical care system and the promising new treatments that are now available. Individuals with AIDS who are now reported are eligible for disability income support programs and Medicare and Medicaid. We believe that before any new system is adopted, we need to further explore the relationship a new CDC initiated HIV surveillance system would have with the programs at the Health Resources Services Administration (HRSA), and the Health Care Financing Administration (HCFA).

Further, AIDS *Action* is especially disappointed that the CDC has not adequately invested resources in the development of non-names based HIV surveillance systems such as Maryland's UI system. States should be encouraged to develop non-names based systems and they should be provided with adequate resources necessary to start-up and perfect these systems. Since non-names systems such as UI's are new to the United States, states choosing this option should be given time to modify and adjust their operations in order to insure maximum effectiveness and reliability of data. Options regarding surveillance systems can only be effectively evaluated if properly funded and all investments including start-up costs are evenly distributed to states (e.g., New Jersey received dollars for creating a name based system whereas Maryland received only evaluation money). **AIDS *Action* recommends that the CDC provide the necessary resources to support the efforts of states to create and improve UI reporting systems and other non names-based surveillance systems without reducing the funding available for prevention programs.**

We are also concerned about your expected endorsement of HIV reporting by name in the November issue of the Morbidity and Mortality Weekly Report (MMWR) coupled with the publication of a study evaluating the UI systems in Maryland and Texas. **AIDS *Action* urges that you reconsider the publication of a CDC**

editorial position at this time. We are also concerned about the publication of the UI evaluation study given CDC's lack of investment in the development of these systems and demonstrated bias regarding support of states that implement HIV surveillance by name.

AIDS *Action* welcomes the opportunity to work with you on this important issue and we will contact you in the next few weeks to set up a meeting. Thank you for your consideration of our views.

Sincerely,

Daniel Zingale
Executive Director

cc: Mr. Kevin DeCock
Ms. Nancy Ann-Min DePearle
Mr. Don Gips
Mr. Josh Gotbaum
Mr. Chris Jennings
Hon. Nancy Pelosi
Mr. David Satcher
Hon. Donna Shalala
Mr. Richard Socarides
Mr. Kevin Thurm
Ms. Sandy Thurman
Mr. John Ward

AIDS ACTION RESOLUTION IN SUPPORT OF HIV REPORTING BY UNIQUE IDENTIFIER AND OTHER NON NAME-BASED SURVEILLANCE SYSTEMS

WHEREAS, AIDS surveillance and AIDS case reporting do not provide an accurate view of the extent of the epidemic nor give a timely and complete indication of trends in the epidemic; and

WHEREAS, generating data which is more representative of the scope of the epidemic can help us better allocate limited resources, target and evaluate prevention efforts, educate the public about the epidemic, and project where the epidemic is going; and

WHEREAS, HIV names reporting may discourage individuals from seeking HIV testing and treatment and the implementation of HIV names reporting is not currently accompanied by guaranteed access to care and treatment; and

WHEREAS, no strong federal privacy law governing health information currently exists and state privacy protections are inadequate; and

WHEREAS, recent court decisions suggest limited or no discrimination protections for asymptomatic HIV positive individuals under the Americans with Disabilities Act (ADA); and

WHEREAS, the negative aspects of name reporting, in the absence of guaranteed access to health care and strong privacy protections, outweigh the potential benefits of this approach; and

WHEREAS, non name-based surveillance systems, such as unique identifier reporting and population based sampling, will support the public health goals of providing data which can help us allocate limited resources, targeting and evaluating prevention efforts, educating the public about the epidemic and projecting where the epidemic is going, while protecting confidentiality and not discouraging people from seeking HIV testing.

BE IT RESOLVED:

That AIDS Action supports the development of non name-based HIV surveillance systems, including unique identifiers, to achieve the public health goals of HIV surveillance.

That AIDS Action opposes name based HIV surveillance.

That AIDS Action calls on the federal government to provide the resources necessary to support the efforts of states to create and improve unique identifier reporting systems and other non name-based surveillance systems without reducing the funding available for prevention programs.

That AIDS Action calls on the federal government to require states which have adopted or may adopt a names reporting system to provide and/or continue a publicly-funded anonymous testing option to ensure that individuals are not deterred from seeking HIV testing.

That AIDS Action calls on the Clinton Administration and the United States Congress to move forward expeditiously to enact and implement a strong federal confidentiality law which serves as a minimum standard for protecting the privacy of all health-related information.

That AIDS Action calls on the federal government to initiate efforts to guarantee access to care and treatment for all HIV positive individuals.

Adopted by the Board of Directors of the AIDS Action Council, October 18, 1997

SF AIDS FOUNDATION

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

October 31, 1997

Dear Colleague:

As you know, there has recently been a great deal of discussion about the need for improved HIV surveillance, with much of the debate focusing on the issue of names reporting. In the upcoming months, the U.S. Centers for Disease Control and Prevention (CDC) is expected to issue guidelines encouraging all states to implement an HIV reporting system, and will most likely give preference to a name-based system. After the first of the year, we also expect the introduction of state legislation to mandate reporting of HIV cases by name to public health officials in California.

In anticipation of these potential developments, the San Francisco AIDS Foundation recently issued the enclosed position statement on HIV surveillance and reporting. We hope that you will read it though, and that it will inform your own thinking about this important policy debate.

In summary, while the Foundation agrees that there is a need for improved HIV data -- *if* this information is in fact used to better plan for future service needs and to target and evaluate prevention efforts -- we continue to disagree strongly that HIV *names* reporting is necessary to accomplish this goal, particularly given the potential negative repercussions associated with this type of reporting system. We believe that another HIV reporting system could be developed -- such as reporting via a unique identifier code -- that would not raise the same public health and privacy concerns associated with HIV names reporting. In addition, we absolutely reject the popular misconception that names reporting is necessary in order to improve access to new treatments.

Other advocacy organizations, including the National Association of People with AIDS (NAPWA), AIDS Action Council, AIDS Action Committee of Boston and the American Civil Liberties Union (ACLU) have recently issued similar statements because of concerns about names reporting.

Based on our position statement, the Foundation will advocate adoption of local, state and national surveillance systems that provide useful data while minimizing any potential harm to individuals living with HIV. If you have additional questions, please feel free to contact the Public Policy Department at (415) 487-3080.

Sincerely,

Regina Aragón

Regina Aragón
Deputy Director for Public Policy

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

SF AIDS FOUNDATION
SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

EXECUTIVE SUMMARY OF THE HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION

Changes in the epidemic have led many public health officials to express increasing concern that existing AIDS surveillance efforts are becoming outdated. This has often resulted in the call for some type of HIV reporting system.

The San Francisco AIDS Foundation acknowledges there is a need for improved HIV data, if this information is used appropriately to better plan for future service needs, target and evaluate prevention efforts, and inform resource allocation decisions. **However, we strongly disagree that HIV *names* reporting is necessary to accomplish these goals, and we do not believe that the benefits of names reporting outweigh the potential negative repercussions associated with this type of surveillance system (such as the possibility that some individuals would be deterred from seeking HIV testing and/or treatment under such a system).**

Any system that is developed should meet the goals of HIV surveillance and the criteria by which HIV surveillance systems should be evaluated that are outlined below. Non-names based surveillance systems that may be able to meet these goals and criteria, such as reporting systems that utilize unique identifiers, must be more aggressively examined in an unbiased fashion as a viable alternative to HIV names reporting.

Goals and Appropriate Uses of HIV Surveillance Data

We believe that HIV surveillance should only be designed to help meet the following goals:

- Better determine and understand the demographic and risk profiles of the current epidemic;
- Plan for future health care and social service needs;
- Track new incidence of HIV in order to target prevention efforts;
- Evaluate overall efficacy of prevention efforts;
- Inform rational resource allocation.

Any HIV surveillance system that is developed should include specific mechanisms to ensure that surveillance data is utilized to meet these goals. In addition, although certain activities are worthy goals of HIV testing and treatment programs—such as linking individuals to care and treatment or identifying additional individuals who have possibly been exposed to HIV—these are not appropriate uses of HIV surveillance data. HIV reporting will not make treatment more available or accessible and is not needed to conduct effective partner notification.

Criteria That Should Be Utilized to Evaluate HIV Surveillance Efforts

The Foundation believes there are reasonable and appropriate criteria that must be met to justify the use of any particular HIV surveillance system. Specifically, an HIV surveillance system should:

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

SF AIDS FOUNDATION

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION

Introduction

Changes in the epidemic have led many public health officials to express increasing concern that existing AIDS surveillance efforts are becoming outdated. Because new treatment options are thankfully slowing or stopping disease progression in many individuals living with HIV, greater numbers of individuals are not progressing to AIDS. These individuals are therefore not being reported systematically to public health entities (since in California and many other states, only AIDS cases are reportable). As a result, some public health officials have argued that AIDS case data are becoming less indicative of both the number and the demographics of individuals who are actually HIV-infected. Often, this has led to the call for HIV names reporting, whereby all individuals living with HIV would be reported by name and other identifying information to their local and/or state health departments.

The San Francisco AIDS Foundation acknowledges there is a need for improved HIV data, if this information is used appropriately to better plan for future service needs, target and evaluate prevention efforts, and inform resource allocation decisions. **However, we strongly disagree that HIV *names* reporting is necessary to accomplish these goals, and we do not believe that the benefits of names reporting for people living with HIV outweigh the potential negative repercussions associated with this type of surveillance system (such as the possibility that some individuals would be deterred from seeking HIV testing and/or treatment under such a system).**

Although the Foundation remains strongly opposed to mandatory names reporting, other HIV surveillance and/or reporting systems may be available or developed that could provide better data regarding the HIV epidemic without having the potentially negative impact of names reporting. This could include some type of HIV reporting by unique identifiers, in which an individual is assigned a unique and confidential code that is reported, expanded use of seroprevalence and seroincidence studies, or some other type of surveillance mechanism.

The remainder of this document outlines what we believe are the goals and appropriate uses of HIV surveillance systems, as well as criteria that should be used to judge any HIV surveillance system that is implemented. Non-names based surveillance systems that may be able to meet these goals and criteria, such as reporting systems that utilize unique identifiers, must be more aggressively examined in an unbiased fashion as a viable alternative to HIV names reporting.

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

Goals and Appropriate Uses of HIV Surveillance

We believe that HIV surveillance should only be designed to help meet the following goals:

- **Better determine and understand the demographic and risk profiles of the current epidemic.** Relying exclusively or primarily on AIDS reporting and surveillance makes it difficult to obtain a current "snapshot" of the HIV epidemic, and this is becoming even more problematic as fewer individuals are progressing to AIDS. However, it should be noted that HIV reporting data would be limited in that it would only provide information on those who self-select to be tested at a site where they are reported to government officials and/or those who seek health care for their HIV status. This data would in no way provide comprehensive information on all individuals who are HIV-infected.

- **Plan for future service needs.** The data gathered through HIV surveillance have the potential to provide community planners, leaders, and advocates with information to better assess and plan for upcoming healthcare and support service needs for people living with HIV/AIDS.

- **Track new incidence of HIV in order to target prevention efforts.** Ideally, HIV surveillance data could help us to better identify who is currently becoming infected (i.e. which risk behaviors and/or populations) and identify new trends in the epidemic, so that prevention efforts could be more quickly directed to those individuals at greatest risk for infection.

- **Evaluate overall efficacy of prevention efforts.** Surveillance information could also be used to help in broadly assessing the effectiveness of HIV prevention strategies. If HIV surveillance demonstrates that HIV infections are continuing to increase in a community, this may indicate a need to re-evaluate, alter and/or expand prevention efforts.

- **Inform rational resource allocation.** This data and its ability to assist in planning for future needs and targeting and evaluating prevention efforts could also be used to better inform resource allocation decisions. Surveillance data has the potential to inform both HIV-specific decisions (e.g., to determine funding for different HIV-specific services or for particular HIV-affected populations) and to inform broader, non-HIV specific funding decisions (e.g., determining spending for HIV and/or health care broadly as compared to other services or issues).

Any HIV surveillance system that is developed should include specific mechanisms to ensure that surveillance data are utilized to meet these goals. Far too often, surveillance systems have been developed that do nothing more than collect data, but are never actually used in a meaningful way to plan for improved service delivery or to inform the resource allocation process. It is unacceptable to collect this data without it clearly being used to meet goals that will benefit individuals living with HIV/AIDS. If the data collected through an HIV surveillance and/or reporting system are not actually utilized for these purposes or fail to meet these goals, the

surveillance system should be terminated and any resources being used to implement such a system should be redirected to other urgent health care needs.

In addition, the Foundation believes that the goals listed above are the *only* legitimate and justifiable goals of HIV surveillance. Other ways in which HIV surveillance information could be used have been identified, such as increasing direct access to HIV care and treatment and identifying additional individuals who have possibly been exposed (e.g. partner notification efforts). Although these are worthy goals of HIV testing and treatment programs, the Foundation does not agree that these are appropriate goals for HIV surveillance. Specifically:

- **HIV surveillance and/or reporting will not make treatment more available or accessible.** Instead, adequate funding levels of HIV care and treatment services are needed to expand access to new HIV treatments. San Francisco serves as an exemplary model for getting individuals tested and into early treatment and care not because of any sort of HIV reporting system, but because the City has assured adequate funding for these services. HIV surveillance or reporting will not in any way expand or improve access to care services.

- **HIV reporting is not needed to conduct effective partner notification.** Partner notification programs are already in place throughout California without any type of HIV reporting. If an individual is offered counseling on how to tell his or her previous partners about possible exposure to HIV or given the opportunity to have the local health department notify these partners, there is no need to have the initial case reported to the government. In fact, HIV reporting by name could actually *discourage* partner notification efforts because some individuals might be more reluctant to provide information about their partners if they know that their own name is going to be reported to a governmental entity.

Surveillance and reporting efforts have also been justified or used in extraordinarily inappropriate ways that actually harm or punish people living with HIV/AIDS. Specifically, HIV surveillance or reporting systems must be designed so that they can never be utilized to: (1) quarantine those with HIV; (2) penalize and/or criminalize individuals accused of transmitting or exposing others to HIV; or (3) assist in coercive efforts to mandate use of HIV treatments. In addition, these systems should never be used to create and/or maintain a perception the government is appropriately and adequately responding to the epidemic. HIV surveillance and/or reporting funding should in no way replace current prevention efforts or care and treatment services.

Finally, some have argued that HIV should be reportable in order to ensure that standard public health tools are applied to HIV. The Foundation does not believe that this justification, in and of itself, is a necessary or important goal. Unless applying standard public health tools to HIV actually meets the appropriate goals of HIV surveillance that are identified above, there is not an inherent value to applying these tools. Furthermore, these public health tools have not proven themselves to be unilaterally effective in stemming the spread of other diseases and their usefulness must be evaluated in regards to each particular public health issue. Any system that is implemented should be designed in a way that acknowledges both the strengths and weaknesses of "traditional" surveillance systems and public health methods.

Criteria That Should Be Utilized to Evaluate HIV Surveillance Efforts

As noted above, the Foundation agrees that improved surveillance efforts have the potential to improve HIV prevention efforts as well as care service delivery and planning. However, we also recognize that these same systems can have negative consequences for people living with HIV and those at risk for HIV infection, such as deterring individuals from seeking testing and/or treatment, shifting resources from other HIV services into surveillance, and violating individuals' confidentiality and/or civil rights. It is absolutely critical that we examine the trade-offs between obtaining better data and possible negative impact of this process. Thus, there must be a careful examination of any surveillance or reporting system that is proposed.

The Foundation believes there are reasonable and appropriate criteria that must be met to justify the use of any particular HIV surveillance system. Specifically, an HIV surveillance system should.

- **Not create a disincentive to testing and/or treatment.** Several studies have shown that some HIV reporting systems (in particular, names reporting) may reduce people's willingness to get tested. Given that an estimated one-third of those believed to be HIV-infected have never been tested, surveillance systems should not in any way discourage individuals at high risk for HIV infection from being tested. Specifically, anonymous testing must remain accessible and available to anyone who would prefer this testing option. Anonymous testing must be accessible geographically (i.e., individuals should not have to travel great distances to obtain anonymous testing), at convenient hours (including times in which individuals are not working), and should be provided free of any charges or fees.

  However, the availability of anonymous testing is not sufficient to address these concerns. Some individuals might get tested anonymously, find out that that they were HIV infected and then avoid treatment because of fear of being reported to the government when accessing the health care setting. In light of the treatment options that now exist, it is more important than ever that individuals be encouraged to seek HIV testing and early treatment. Any HIV surveillance system that is developed must also minimize individuals' concerns so that they are not discouraged from seeking early care and treatment. Mandated reporting by name would be the most likely system to increase individuals' reluctance to seek treatment.

- **Produce information that is actually utilized for planning and evaluation purposes in a manner that has the potential to improve the community's health.** As discussed in the goals section, it is absolutely critical that this surveillance data actually serve an important public health role in providing useful and timely information that is used to inform community planning and target and evaluate prevention efforts. If a surveillance system does not prove to be useful in this regard after its implementation, this data collection exercise should be stopped. Specifically, this data should clearly provide individuals living with HIV and those at risk for HIV infection with meaningful information to make decisions for themselves and should be used to ensure adequate availability of care and treatment services for people living with HIV.

In addition, surveillance data should provide useful and timely information that is accessible to the community (i.e., the data should be shared and widely distributed within the community). If the data is not timely or accessible, it will not provide sufficient benefit to people living with HIV to justify such a system.

It should also be noted that such data does not have to be 100% accurate and complete to provide useful information in discerning trends in the epidemic and planning for future service needs. Even with the most accurate data on AIDS cases, there is often a significant time lag between the AIDS diagnosis and the report to public health officials. Incomplete or imperfect data will certainly provide more information than we now have available, which would greatly help in determining broad trends in the epidemic. Accurate trend data is the most important information needed in order to conduct thoughtful planning.

- **Not violate confidentiality and/or civil rights and should include strong enforcement and penalties for disclosure of information.** Surveillance systems have the potential to be used for inappropriate purposes, such as utilizing lists to demonstrate knowledge of HIV status when attempts are made to punish individuals accused of exposing others to HIV infection. Although health departments have generally been extremely careful with this type of information, these departments could be compelled by legislative mandate or judicial order to surrender HIV case reports. For example, a recent United States Department of Health and Human Services proposal could lead to expanded law enforcement access to medical records. It is possible that this could include public health records, such as HIV case reports. In addition, although breaches by public health officials have been rare, they have occurred (most dramatically in Florida in 1996), and greatly increase community and individual concerns regarding confidentiality and privacy.

  Given the possibility of potential breaches in confidentiality, as well as the strong incentives of HMOs and other managed care entities and insurers to obtain such lists, it is critical that any system that is implemented make every effort to minimize—if not eliminate—the possibility of such disclosures. Any sort of named reporting of HIV infection clearly violates this principle and greatly increases the possibility for breaches and/or legislative mandate to disclose who is HIV infected. Finally, in order to minimize the potential for disclosure there should be extensive and enforceable penalties applied to anyone who tries to inappropriately access health department HIV case information or any health department personnel who disclose an individual's HIV status.

- **Not come at the expense of resources for treatment/services.** Although increased data could potentially be useful for planning and evaluation purposes, its benefit will be eliminated if resources for care or prevention services are re-directed to fund surveillance systems. Although surveillance data may be useful, it in no way supplants the need for adequate funding for HIV prevention and care services. In addition, the government must not use expenditures on HIV surveillance to indicate that something is being done to fight the epidemic. Counting cases is not equivalent to responding to the epidemic.

- **Respect individual choice with respect to name disclosure.** Any HIV surveillance system that is developed should provide individuals with the option not to have their names or other identifying information reported to the government. By ensuring this choice, the system will

reduce the potential for deterrence to testing and/or treatment as well as the likelihood of misuse of the information, thus minimizing the potential for negative consequences. This also helps to ensure that individuals living with HIV and those at risk for HIV infection have some control over the information that is available about them and minimizes the invasiveness of such surveillance systems. Given the mistrust of government in today's society, particularly among disenfranchised populations, individuals must be allowed to decide for themselves if they want identifying information provided to governmental entities.

Simply guaranteeing the availability of anonymous testing does not address this concern. If a names reporting system were instituted, individuals would have no control over the disclosure of their name when they accessed early treatment. The system must respect individuals' decisions about their names being reported or disclosed to public health authorities at not only the point of HIV testing, but also when individuals seek HIV care services.

Thus, mandatory names reporting should under no circumstances be required or encouraged. Other systems that do not rely on names, such as some type of unique identifier system that also meets the other criteria listed above, should be pursued if it is decided that HIV surveillance data is necessary and will be utilized in a manner that promotes the community's health.

The Foundation will remain opposed to any HIV surveillance system that does not meet the above criteria. Only by meeting these criteria will a system provide sufficient benefit to the community to outweigh any potential negative or damaging consequences.

Unique Identifier Reporting Must Be Examined as a Viable Alternative

The primary HIV surveillance system that is considered a potential alternative to names reporting is unique identifier reporting. Under such a system, an HIV-infected individual would not be reported by name to public health officials but rather by some form of a unique code that could not be traced back to the person. These types of systems use letters or numbers to represent data elements such as race, gender, and date of birth, which create a code with a high degree of uniqueness. Theoretically, this code is unique to the individual for whom it is developed (so that no one else is reported with the same identifier), and would be easily replicated every time the person is reported, thus ensuring an unduplicated count of HIV cases.

Unique identifier reporting has been seen as a potential compromise between those who strongly believe that better HIV data is needed and those who have strong public health and privacy concerns regarding HIV names reporting. Unfortunately, the experience with unique identifier reporting for HIV infection has been rather limited in the United States. Only two states—Maryland and Texas—have implemented such systems, and these have only been in place since 1994. Because these systems are the only ones that exist in the nation, they have been carefully scrutinized and compared to HIV names reporting systems in other states. Many have argued that the data regarding the effectiveness of these systems are not promising and have shown that these systems provide less complete information than that provided through names based reporting. This has led many to conclude that names reporting is the only viable HIV surveillance system available.

The Foundation disagrees with this conclusion. We do not believe that unique identifier reporting systems have been judged fairly in the national debate regarding HIV surveillance systems. Specifically:

- **Unique identifier systems have not been funded adequately.** While the CDC provides funding to states to implement names based reporting, relatively little financial support has been provided for unique identifier systems by either federal or state governments. Lack of resources has limited the ability to implement a system that is as effective as possible.

- **The evaluation of the current unique identifier systems has not adequately taken into account the fact that these systems are relatively new.** Both Texas and Maryland began implementing their systems in March of 1994, only a little over three years ago. The relative youth of these systems must be kept in mind when evaluating their effectiveness. These systems are bound to improve over time. To the extent that evaluations of these systems have shown potential problems, this information can and should be used to improve and build upon the existing systems and/or to assist in crafting new and better systems.

- **The standard used to judge unique identifier systems has been set unnecessarily high.** As noted above, absolutely complete and accurate data is not needed to analyze broad trends in the epidemic. Although the completeness of information provided by unique identifier reporting has not been as high as name-based reporting, it would certainly provide much more information than we currently have about emerging trends in the epidemic. This new data will significantly improve our ability to plan for upcoming health care and social service needs and appropriately target and evaluate prevention activities.

- **The fact that many states have implemented names-based reporting does not provide a legitimate rationale for opposing unique identifier reporting.** Some have argued that because 28 states currently require HIV names reporting, all other states should follow suit to ensure that there is a consistent reporting mechanism across the country. However, it is estimated that 75% of individuals living with HIV infection reside in states that do not require HIV case reporting by name. A national system must be designed to meet the legitimate public health needs of all states—including those with the largest percentage of people living with the disease.

The presumption that name-based reporting is the only effective system and the easiest to implement has led many to reject unique identifiers or other possible systems out-of-hand. The Foundation believes that if public health officials commit to providing proper attention and time to developing such a system, a reporting mechanism could be developed that would provide adequate and necessary surveillance data while greatly reducing the public health and privacy concerns related to name based reporting.

In conclusion, the Foundation certainly agrees that improved HIV surveillance data, if used appropriately, could benefit people living with HIV. However, collection of this data must be done in a manner that minimizes the potential for harm to these same individuals. We will continue to work to establish a system that meets both of these important goals.

VII. STATE/LOCAL USE ONLY

Physician's Name: _____ Phone No.: ( ) _____ Medical Record No. _____
(Last, First, M.I.)

Hospital/Facility: _____ Person Completing Form: _____ Phone No.: ( ) _____

– Physician identifier information is not transmitted to CDC! –

VIII. CLINICAL STATUS

CLINICAL RECORD REVIEWED: Yes [1] No [0]

ENTER DATE PATIENT WAS DIAGNOSED AS: Asymptomatic (including acute retroviral syndrome and persistent generalized lymphadenopathy): Mo. [ ][ ] Yr. [ ][ ]

Symptomatic (not AIDS): Mo. [ ][ ] Yr. [ ][ ]

AIDS INDICATOR DISEASES	Initial Diagnosis Def.	Initial Diagnosis Pres.	Initial Date Mo.	Initial Date Yr.
Candidiasis, bronchi, trachea, or lungs	[1]	NA	[ ][ ]	[ ][ ]
Candidiasis, esophageal	[1]	[2]	[ ][ ]	[ ][ ]
Carcinoma, invasive cervical	[1]	NA	[ ][ ]	[ ][ ]
Coccidioidomycosis, disseminated or extrapulmonary	[1]	NA	[ ][ ]	[ ][ ]
Cryptococcosis, extrapulmonary	[1]	NA	[ ][ ]	[ ][ ]
Cryptosporidiosis, chronic intestinal (>1 mo. duration)	[1]	NA	[ ][ ]	[ ][ ]
Cytomegalovirus disease (other than in liver, spleen, or nodes)	[1]	NA	[ ][ ]	[ ][ ]
Cytomegalovirus retinitis (with loss of vision)	[1]	[2]	[ ][ ]	[ ][ ]
HIV encephalopathy	[1]	NA	[ ][ ]	[ ][ ]
Herpes simplex: chronic ulcer(s) (>1 mo. duration); or bronchitis, pneumonitis or esophagitis	[1]	NA	[ ][ ]	[ ][ ]
Histoplasmosis, disseminated or extrapulmonary	[1]	NA	[ ][ ]	[ ][ ]
Isosporiasis, chronic intestinal (>1 mo. duration)	[1]	NA	[ ][ ]	[ ][ ]
Kaposi's sarcoma	[1]	[2]	[ ][ ]	[ ][ ]

AIDS INDICATOR DISEASES	Initial Diagnosis Def.	Initial Diagnosis Pres.	Initial Date Mo.	Initial Date Yr.
Lymphoma, Burkitt's (or equivalent term)	[1]	NA	[ ][ ]	[ ][ ]
Lymphoma, immunoblastic (or equivalent term)	[1]	NA	[ ][ ]	[ ][ ]
Lymphoma, primary in brain	[1]	NA	[ ][ ]	[ ][ ]
Mycobacterium avium complex or *M.kansasii*, disseminated or extrapulmonary	[1]	[2]	[ ][ ]	[ ][ ]
M. tuberculosis, pulmonary*	[1]	[2]	[ ][ ]	[ ][ ]
M. tuberculosis, disseminated or extrapulmonary*	[1]	[2]	[ ][ ]	[ ][ ]
Mycobacterium, of other species or unidentified species, disseminated or extrapulmonary	[1]	[2]	[ ][ ]	[ ][ ]
Pneumocystis carinii pneumonia	[1]	[2]	[ ][ ]	[ ][ ]
Pneumonia, recurrent, in 12 mo. period	[1]	[2]	[ ][ ]	[ ][ ]
Progressive multifocal leukoencephalopathy	[1]	NA	[ ][ ]	[ ][ ]
Salmonella septicemia, recurrent	[1]	NA	[ ][ ]	[ ][ ]
Toxoplasmosis of brain	[1]	[2]	[ ][ ]	[ ][ ]
Wasting syndrome due to HIV	[1]	NA	[ ][ ]	[ ][ ]

Def. = definitive diagnosis Pres. = presumptive diagnosis

* RVCT CASE NO.: [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

- **If HIV tests were not positive or were not done, does this patient have an immunodeficiency that would disqualify him/her from the AIDS case definition?** [1] Yes [0] No [9] Unknown

IX. TREATMENT/SERVICES REFERRALS

Has this patient been informed of his/her HIV infection? [1] Yes [0] No [9] Unk.

This patient's partners will be notified about their HIV exposure and counseled by:
[1] Health department [2] Physician/provider [3] Patient [9] Unknown

This patient is receiving or has been referred for:

	Yes	No	NA	Unk.
• HIV related medical services	[1]	[0]	–	[9]
• Substance abuse treatment services	[1]	[0]	[8]	[9]

This patient received or is receiving:

	Yes	No	Unk.
• Anti-retroviral therapy	[1]	[0]	[9]
• PCP prophylaxis	[1]	[0]	[9]

This patient has been enrolled at:

Clinical Trial	Clinic
[1] NIH-sponsored	[1] HRSA-sponsored
[2] Other	[2] Other
[3] None	[3] None
[9] Unknown	[9] Unknown

This patient's medical treatment is primarily reimbursed by:
[1] Medicaid [2] Private insurance/HMO
[3] No coverage [4] Other Public Funding
[7] Clinical trial/ government program [9] Unknown

FOR WOMEN:
- This patient is receiving or has been referred for gynecological or obstetrical services: [1] Yes [0] No [9] Unknown
- Is this patient currently pregnant? [1] Yes [0] No [9] Unknown
- Has this patient delivered live-born infants? [1] Yes (if delivered after 1977, provide birth information below for the most recent birth) [0] No [9] Unknown

CHILD'S DATE OF BIRTH: Mo. [ ][ ] Day [ ][ ] Yr. [ ][ ]

Hospital of Birth: _____ City: _____ State: _____

Child's Soundex: [ ][ ][ ][ ]

Child's State Patient No.: [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

X. COMMENTS: _____

I. STATE/LOCAL USE ONLY

Patient's Name: _____ Phone No.: ( ) _____
(Last, First, M.I.)

Address: _____ City: _____ County: _____ State: _____ Zip Code: _____

RETURN TO STATE/LOCAL HEALTH DEPARTMENT — *– Patient identifier information is not transmitted to CDC! –*

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service

ADULT HIV/AIDS CONFIDENTIAL CASE REPORT
(Patients ≥13 years of age at time of diagnosis)

CDC — CENTERS FOR DISEASE CONTROL AND PREVENTION

II. HEALTH DEPARTMENT USE ONLY

Form Approved OMB No. 0920-0009

DATE FORM COMPLETED: Mo. Day Yr.

REPORT SOURCE:

SOUNDEX CODE:

REPORT STATUS: [1] New Report [2] Update

REPORTING HEALTH DEPARTMENT: State: City/County:

State Patient No.:

City/County Patient No.:

III. DEMOGRAPHIC INFORMATION

DIAGNOSTIC STATUS AT REPORT (check one):
[1] HIV Infection (not AIDS)
[2] AIDS

AGE AT DIAGNOSIS: ____ Years ____ Years

DATE OF BIRTH: Mo. Day Yr.

CURRENT STATUS: Alive [1] Dead [2] Unk. [9]

DATE OF DEATH: Mo. Day Yr.

STATE/TERRITORY OF DEATH: _____

SEX:
[1] Male
[2] Female

RACE/ETHNICITY:
[1] White (not Hispanic) [2] Black (not Hispanic) [3] Hispanic
[4] Asian/Pacific Islander [5] American Indian/ Alaska Native [9] Not Specified

COUNTRY OF BIRTH:
[1] U.S. [7] U.S. Dependencies and Possessions (including Puerto Rico) (specify): _____
[8] Other (specify): _____ [9] Unknown

RESIDENCE AT DIAGNOSIS:
City: _____ County: _____ State/ Country: _____ Zip Code: _____

IV. FACILITY OF DIAGNOSIS

Facility Name _____

City _____

State/Country _____

FACILITY SETTING (check one)
[1] Public [2] Private [3] Federal
[9] Unknown

FACILITY TYPE (check one)
[01] Physician, HMO [31] Hospital, Inpatient
[88] Other (specify): _____

This report is authorized by law (Sections 304 and 306 of the Public Health Service Act, 42 USC 242b and 242k). Response in this case is voluntary for federal government purposes, but may be mandatory under state and local statutes. Your cooperation is necessary for the understanding and control of HIV/AIDS. Information in the surveillance system that would permit identification of any individual on whom a record is maintained, is collected with a guarantee that it will be held in confidence, will be used only for the purposes stated in the assurance on file at the local health department, and will not otherwise be disclosed or released without the consent of the individual in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

V. PATIENT HISTORY

AFTER 1977 AND PRECEDING THE FIRST POSITIVE HIV ANTIBODY TEST OR AIDS DIAGNOSIS, THIS PATIENT HAD (Respond to **ALL** Categories):

	Yes	No	Unk.
• Sex with male	1	0	9
• Sex with female	1	0	9
• Injected nonprescription drugs	1	0	9
• Received clotting factor for hemophilia/coagulation disorder	1	0	9
Specify disorder: [1] Factor VIII (Hemophilia A) [2] Factor IX (Hemophilia B) [8] Other (specify): _____			
• *HETEROSEXUAL* relations with any of the following:			
• Intravenous/injection drug user	1	0	9
• Bisexual male	1	0	9
• Person with hemophilia/coagulation disorder	1	0	9
• Transfusion recipient with documented HIV infection	1	0	9
• Transplant recipient with documented HIV infection	1	0	9
• Person with AIDS or documented HIV infection, risk not specified	1	0	9
• Received transfusion of blood/blood components (other than clotting factor)	1	0	9
First Mo. Yr. Last Mo. Yr.			
• Received transplant of tissue/organs or artificial insemination	1	0	9
• Worked in a health-care or clinical laboratory setting	1	0	9
(specify occupation): _____			

VI. LABORATORY DATA

1. HIV ANTIBODY TESTS AT DIAGNOSIS: (Indicate first test)

	Pos	Neg	Ind	Not Done	TEST DATE Mo.	Yr.
• HIV-1 EIA	1	0	–	9		
• HIV-1/HIV-2 combination EIA	1	0	–	9		
• HIV-1 Western blot/IFA	1	0	8	9		
• Other HIV antibody test (specify): _____	1	0	8	9		
• HIV-2 EIA	1	0	–	9		
• HIV-2 Western blot	1	0	8	9		

2. POSITIVE HIV DETECTION TEST: (Record earliest test)

	Mo.	Yr.
• HIV culture		
• HIV antigen test		
• HIV PCR, DNA or RNA probe		
• Other (specify): _____		

	Yes	No	Unk.
• If HIV laboratory tests were not documented, is HIV diagnosis documented by a physician?	1	0	9

If yes, provide date of documentation by physician. ..... Mo. Yr.

• Date of last documented negative HIV test (specify type): _____ Mo. Yr.

3. IMMUNOLOGIC LAB TESTS:

AT OR CLOSEST TO CURRENT DIAGNOSTIC STATUS

		Mo.	Yr.
• CD4 Count	,___ cells/µL		
• CD4 Percent	%		

First <200 µL or <14%

		Mo.	Yr.
• CD4 Count	,___ cells/µL		
• CD4 Percent	%		

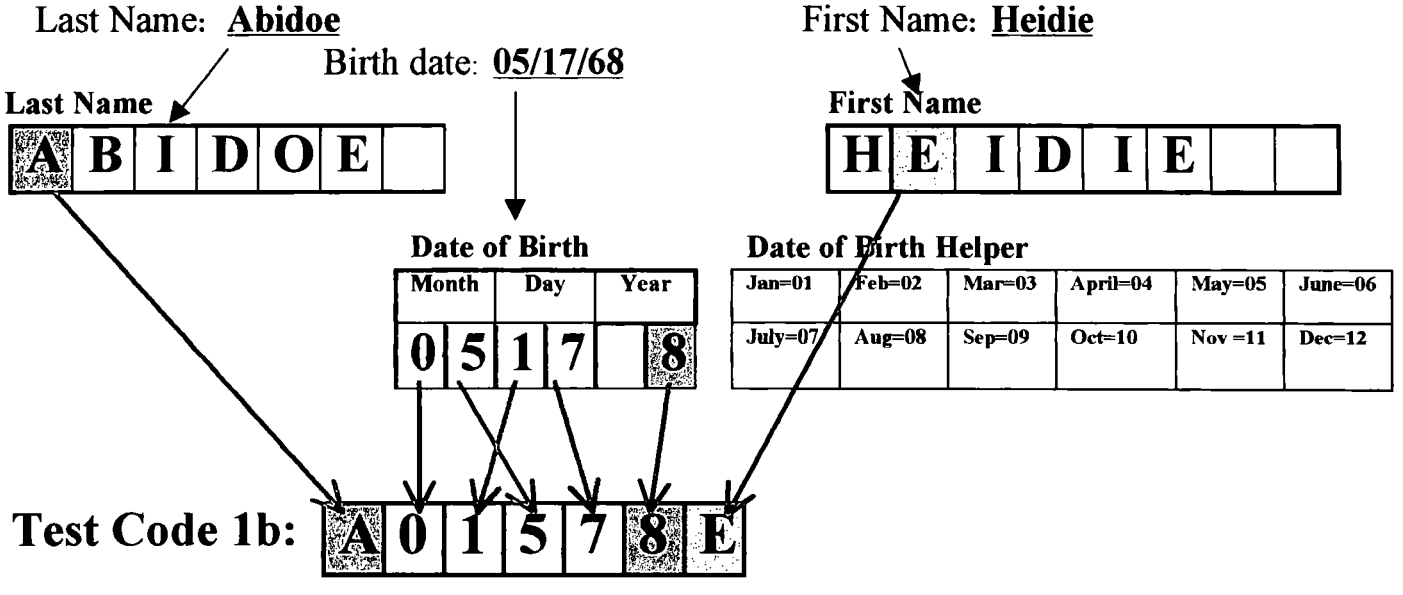
Hawaii Department of Health

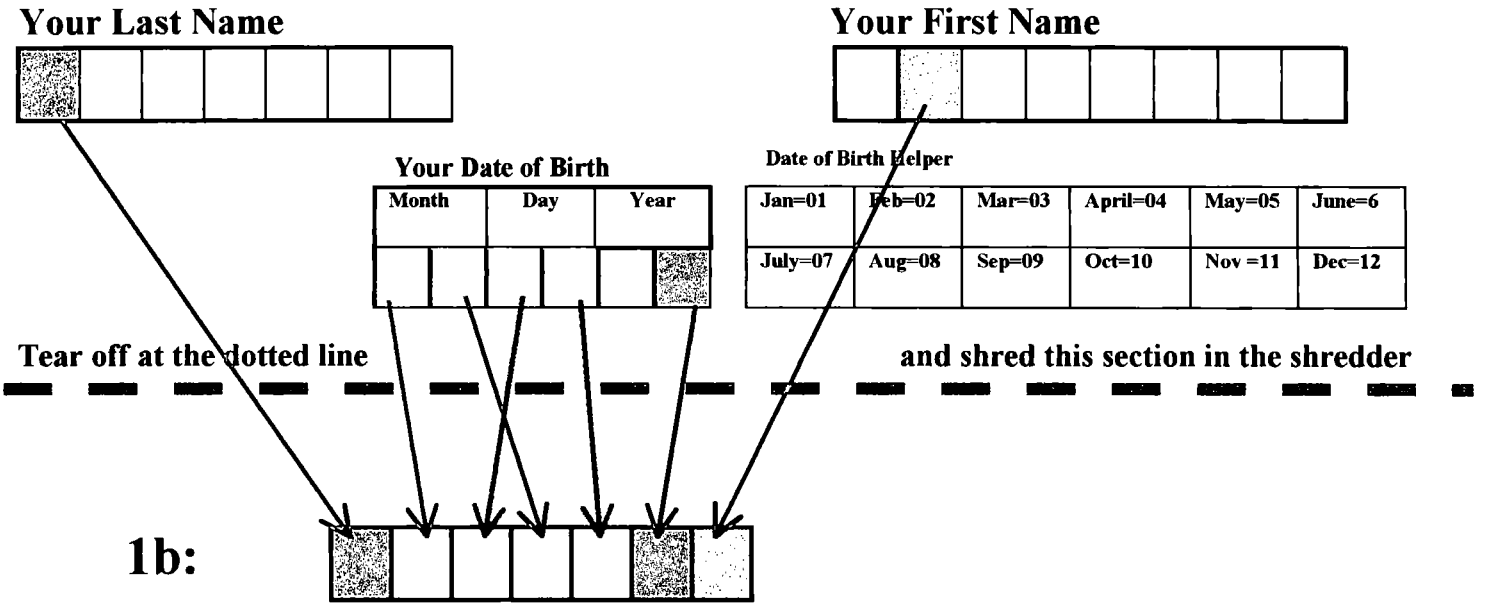
Survey of the Anonymous Test Code

This is a survey of sample Test Codes for possible future HIV reporting in Hawaii. This information is for our survey only and **is not related to your anonymous HIV test today**. Please follow the instructions to create your test code, then complete the survey on the next page. After completing test code and survey questions, **drop off the next page below dotted line in the "Survey Drop Off" box**. Thank you for your time.

Instructions:
Create the Anonymous Test Code by matching the colors and arrows as you can see in the example below.

Example: My name is Heidie Abidoe and my birthday is May17, 1968





Directions:

- After completing your test code, tear off the section of this page at the dotted line.
- Please complete the following questions and drop this section in the "Survey Drop Off" box.
- You may shred the section above the dotted line in the shredder and discard the page 1.

Survey Questions:	**Yes**	**No**
1. Was it difficult to create the test code? Comments?		
2. Were the instructions clear and helpful? Comments?		
3. Look at the anonymous test code above. Do you think anyone would be able to figure out your identity if they saw this test code?		
4. If you had to use this test code, would you still take the HIV test here? Comments?		
5. Additional comments?		

Thank you again for taking time to help with this survey.

95.3% Uniqueness

Test Code 1b: A 0 1 5 7 8 E

Q 1.		Q2.		Q3.		Q4.		Q5.
Yes	No	Yes	No	Yes	No	Yes	No	# of Comments
2	18	18	2	1	16	19	0	0

98.9% Uniqueness

Test Code 3b: A 5 1 6 7 8 E

Q 1.		Q2.		Q3.		Q4.		Q5.
Yes	No	Yes	No	Yes	No	Yes	No	# of Comments
2	18	18	2	1	18	19	0	7

97.8% Uniqueness

Test Code 4b: A 0 1 5 7 8 H

Q 1.		Q2.		Q3.		Q4.		Q5.
Yes	No	Yes	No	Yes	No	Yes	No	# of Comments
3	17	18	2	2	18	19	0	8

99.4% Uniqueness

Test Code 5 b: A 5 1 7 6 8 H

Q 1.		Q2.		Q3.		Q4.		Q5.
Yes	No	Yes	No	Yes	No	Yes	No	# of Comments
1	19	17	3	4	16	19	1	3

96.4% Uniqueness

Test Code 6b: B 0 5 6 7 8 H

Q 1.		Q2.		Q3.		Q4.		Q5.
Yes	No	Yes	No	Yes	No	Yes	No	# of Comments
2	28	29	1	3	26	28	3	6

Activists oppose reporting HIV names

State officials insist 'no decision has been made'

by LAURA BROWN

From attorneys and doctors to indigent patients on public assistance, more than 150 people infected or affected by HIV spoke out unanimously at a town hall meeting April 16 against a proposed plan to collect names of HIV-positive Georgians in order to better track the spread of the disease.

Many of those attending the heated town hall meeting returned the next morning, when the Georgia Task Force on AIDS heard testimony on HIV surveillance from the national Centers for Disease Control, area AIDS service providers and the general public. With the exception of the CDC's Dr. John Ward, sentiments again ran unanimously against names reporting.

AIDS advocates suggested, as an alternative to reporting the names of those with HIV, that Georgia consider reporting HIV cases using a "unique identifier" of numbers and letters, similar to systems in use in Texas and Maryland. While Texas officials have criticized their system for incomplete data and are considering moving to names reporting, Maryland is calling their program a guarded success.

SisterLove Executive Director Dazon Dixon and Atlanta attorney Chip Rowan were among those voicing criticism of plans to collect the names of Georgians carrying the HIV virus.

In "UI" systems, a code made up of unchangeable data elements such as a certain letter of a patient's name, a partial social security number, or even a standard hand measurement are compiled to create a unique code for each person who tests positive for HIV.

➢ Continued on Page 19

Georgia Equality Project turns the corner, leaders say

by LAURA BROWN

The Georgia Equality Project Foundation

steward of the community's money" was one of the chief concerns raised at their last public forum in February.

aside 15 percent of monthly income to hire staff or consultants to monitor the 1999 Legislature, but Knox said limited finances

Reporting HIV names

➢ Continued from Page 7

Public health officials can then monitor the spread of HIV in order to target prevention and services, while those tested can feel more secure because "their names won't be on any list," UI supporters said.

Dr. Melanie Thompson, principal researcher for the AIDS Research Consortium of Atlanta, AIDS Survival Project Executive Director Jeff Graham, SisterLove founder Dazon Dixon, AID Atlanta's Craig Washington and civil rights attorney Chip Rowan were among the community leaders who said they oppose names reporting. Still, each speaker offered only a personal viewpoint; none spoke on behalf of AIDS service organizations.

Neither the Task Force nor the Georgia Department of Human Resources has made a decision about what form of HIV surveillance to conduct, officials stressed. DHR's David Johnson said the agency will conduct public hearings in all 19 Georgia health districts before October and will take at least a year to reach a final decision.

"The one thing I want you to hear is we have not made a decision yet, and we will not make a decision in a vacuum," he promised. "We want buy-in from the entire community, and if we don't have that, we all lose."

Although all 50 states currently monitor cases of full-blown AIDS using names, that information is kept on the state level and only statistics are tracked nationally.

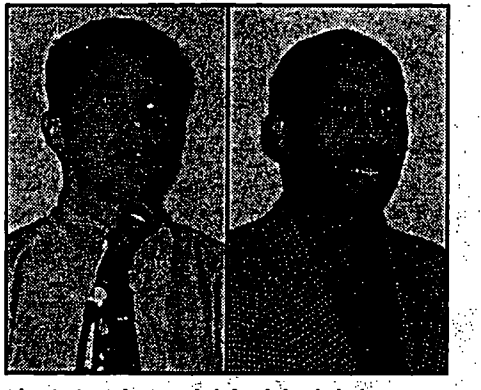
Opponents to HIV-names reporting said they fear the program would deter testing, and it could be vulnerable to both illegal and legal confidentiality breaches.

More disturbing than the possibility that someone could violate policy and "leak the list," they said, is the fear that increasingly conservative state legislatures could repeal confidentiality laws that would protect HIV-positive people from exposure.

"I can say sincerely that I believe the DHR has people's best interests at heart, but I don't trust the legislature," ASP's Graham said. "To over-generalize the Georgia legislature, they never cared about HIV at all, they hate gay men, they've never cared much for people of color, and if you are an IV drug user, you deserve to die."

According to Anna Forbes, a consultant and UI researcher who spoke at the town hall meeting, in 1991 the Illinois legislature passed a law requiring its health department to identify HIV-positive health care providers by cross-matching the state AIDS registry with licensing records.

The law further required the department to contact all the HIV-positive providers' patients, Forbes said, but community pressure kept it from being funded and therefore implemented.



The CDC's John Ward (left) defended plans to report the names of Georgians with HIV, but state official David Johnson promised that his agency had made no final decision.

UI proponents said they fear even more widespread misuse of HIV-lists, and cited criminal prosecutions as another area for potential problems. As states move to criminalize exposing a sex partner to HIV infection as attempted murder, they asked, what will keep prosecutors from getting subpoenas to see if defendants' names are on the HIV registry?

"The only safe list is the list that is never created," Forbes concluded, drawing applause from forum attendees.

In favor of names reporting, meanwhile, the CDC's Ward said the system has less chance for duplication or incomplete data then constructing a UI code, and will be easier to implement because health care providers are already accustomed to keeping other medical records using names.

NationsBank

➢ Continued from Page 7

realization that the dependents our employees support might be parents, siblings or domestic partners."

BankAmerica's equal employment opportunity policy also protects gay employees from being fired, denied a promotion or harassed just because of their sexual orientation.

NationsBank, however, does not include sexual orientation in its nondiscrimination policy, and it remains unclear how it will be affected by the merger. "That issue has not been addressed," Waller said.

McColl said that employees will not lose any benefits they now get, and NationsBank workers could gain unspecified ones from the merger.

"Bank of America has many very positive, forward-thinking policies... and basically we'll probably extend them across the franchise after we study everything," he said.

In 1990, only a half-dozen employers offered health and other benefits to same-sex couples. According to the Human Rights Campaign, nearly 500 employers now offer domestic partnership.

Turner Broadcasting Systems, Inc., and Emory University are among the large Atlanta employers offering the benefits.

—From staff writer Laura Brown and wire reports

SERVING THE NATION'S CAPITAL SINCE 1969

The Washington Blade

HIV debate erupts

Distrust of government underlies emotions at HIV reporting forum

by Kai Wright

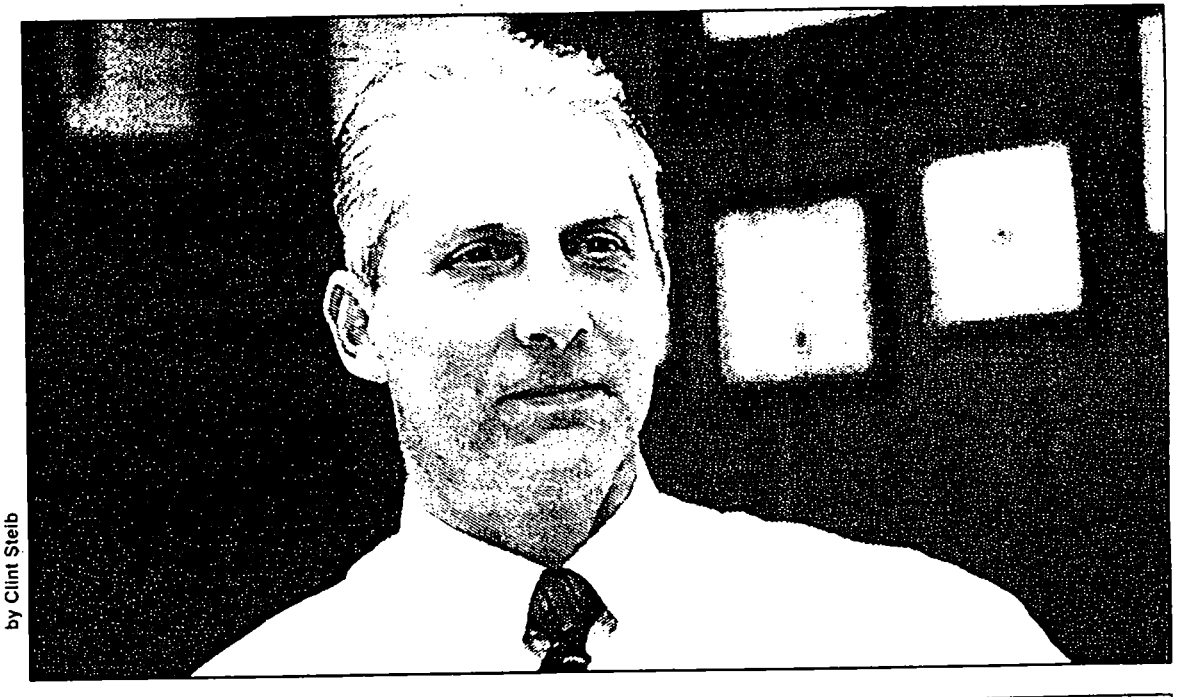
by Clint Steib

"The purpose of this meeting was to get [community] input into developing HIV surveillance," said Allan Noonan.

In an emotionally charged two-hour public forum April 21, the national controversy over if and how public health officials should track new HIV infections hit Washington, D.C. Approximately 100 people, many representing local community-based AIDS organizations, presented local and national public health officials with a clear consensus: The government cannot be trusted to protect sensitive information identifying people living with HIV, particularly if that information is collected in the form of the names of people with HIV.

One speaker after another approached the forum's panel of public health experts, assembled by the D.C. Department of Health (DOH). Many shared personal anecdotes of having been discriminated against because of his or her HIV-positive status. Many recounted incidents in which government officials failed to protect privacy rights when dealing with non-HIV-related health information. And

Continued on page 10



by Clint Steib

Crime solvers

D.C detectives team up to solve Gay murders

by Lou Chibbaro Jr.

A newly created team of D.C. Police homicide detectives will act as specialists in cases involving the murders of Gay men and Lesbians, and the team will take unprecedented steps to reach out to the Gay community for help in solving these cases, the commander of the homicide squad said this week.

by Clint Steib

Homicide Commander Ross Swope said he

. . eaders 'p For . .

HIV reporting debate erupts in D.C.

Continued from page 1

many argued that any system of reporting people with HIV in the District would serve only to deter at-risk populations from voluntarily seeking out an HIV antibody test. People living with HIV in prisons, senior citizens and young people, women who inject illegal drugs and women who are pregnant, immigrants, and Gay and bisexual men of color were all among the groups represented at the microphone. And all pleaded with DOH Director Allan Noonan not to create an HIV reporting system in the District.

Currently, the Washington, D.C., Department of Health (DOH) keeps records of only people with full-blown AIDS, tracking new cases by recording each person's name. Noonan said the forum marked the beginning of deliberations on whether to develop a system for tracking HIV infection as well.

"The purpose of this meeting was to get [community] input into developing HIV surveillance," Noonan told the *Blade* after the meeting. "This is the beginning of our planning for the future. In order to plan for the future, you first gather information. That's what we're doing here."

Whitman-Walker Clinic Deputy Director Pat Hawkins, who sat on the six-member panel of health experts who joined Noonan in addressing the issue, joined the chorus of those in the audience opposing any attempt to develop an HIV reporting system in D.C. Hawkins made the Clinic's stance clear.

"We are opposed to names reporting and, at this point in time, we have serious reservations about 'unique identifiers' as well," Hawkins said, attracting cheers from the audience. "Unique identifier" systems, currently used to count HIV infection cases only by Maryland and Texas, give each individual who tests positive a distinguishing code rather than recording the individual's name.

Hawkins said either system would create "a deterrent to testing." She said that, while city officials could probably be trusted to protect the privacy of persons with HIV and guard information from being used to discriminate against such persons, "you cannot predict what our Congress will do to us in the District."

In his remarks opening the forum, Noonan told the audience that DOH must balance its competing concerns, the need to get accurate data on HIV infection rates against the need to avoid jeopardizing the privacy of people with HIV or making them vulnerable to anti-HIV discrimination which still exists in the city.

Noonan said this issue has become more pressing as new treatments prolonging the life spans of people with HIV/AIDS have become available and their success in prolonging lives has begun placing new demands on public health officials to find and allocate funding and focus their efforts.

Noonan was joined by the U.S. Centers for Disease Control and Prevention's HIV surveillance branch head Dr. John Ward. Ward co-authored a *New England Journal of Medicine* article last October that fanned the flames of the debate over HIV reporting by laying out the case for developing a national system for tracking HIV infections. The CDC was expected to release a report outlining its recommendations for how such a system should work early this year. But that report is still not out, and Ward declined to predict when it would be. States would not be forced to institute the recommendations, but Congress could subsequently condition federal funds for state health programs on compliance with the CDC guidelines.

Currently, every state in the nation has self-imposed requiring health care providers and laboratories to report the names of people diagnosed with full-blown AIDS to state health officials. State officials send these reports, which include a variety of health and demographic information, to the CDC. Information that could identify an individual patient is deleted from the reports sent to the CDC, leaving patient names in the hands of state health officials. The system allows the CDC to develop a national picture of the AIDS epidemic and to direct funding to priority programs.

But no such system exists for tracking the number of people with HIV infection. Currently, according to the CDC, only 28 states, including Virginia, record the names of people with HIV infection. Ward told the April 21 forum, and has argued in similar forums around the country, that the lack of information about the number of HIV cases prevents the CDC from developing a reliable picture of the virus's impact nationally. He said it also makes more difficult CDC's efforts to prevent its spread and focus federal funding on priority programs.

"Our concern is that we are losing our ability to track the HIV epidemic," Ward told the gathering. "AIDS data tells us about treatment ... not about who is getting infected." Ward explained that new treatments forestall the advent of full-blown AIDS for many people with HIV and, thus, that tracking the epidemic from its endpoint is no longer effective.

Debating the numbers

In a discussion in which nearly every speaker cited a different study evaluating the effectiveness of a names-based HIV tracking system, Ward cited a new CDC-funded study conducted by researchers at the University of California at San Francisco. Ward told the gathering that the study, conducted in 1995 and 1996 but, as yet, unpublished, counters other studies that have presented evidence that a names-based HIV tracking system would deter individuals from getting tested. (See related story.) The study found that, of those who had not taken the test, only 2 percent indicated that the primary reason for not doing so was a concern that their names would be reported to the government. He said another 19 percent of those who had not been tested listed that concern as one among others. Ward noted that, among the people who *had* been tested, the percentages were similar. Ward said these results cut across racial and ethnic lines.

But the audience reacted strongly to these findings, interrupting Ward's presentation and demanding to know in which cities the study was conducted and asking for more details about how the sample population was selected. Several individuals shouted Ward down as he attempted to answer those questions, apparently unconvinced that the study's results were valid. One audience member responded to Ward's explanation by asking, sarcastically, if the sample population "included anyone who was sober or awake."

After Ward's presentation, several audience members argued that, regardless of what other studies have found, a names-based reporting system would not work in D.C. La Clinica del Pueblo's Candace Kattar said a names-based reporting system would cripple her organization, which provides counseling and testing for the Latino community. Kattar said that, from January to March, La Clinica informally surveyed people who came in for an HIV test, asking if they would have come if they knew their names would be reported to the government if they tested positive. Kattar said that nearly 85 percent of those that responded said they would not have come in for a test.

"In the population that we serve, there is a serious concern of many people here ... a great fear of the Immigration and Naturalization Service. And they live with that fear," Kattar told DOH officials during the forum's question and answer period. She predicted that the institution of a names-based reporting system would spark a "backlash" among La Clinica's clients, driving many to not only refuse to get HIV tests but also to stop taking advantage of other clinic programs.

Ward said that all the concerns presented during the April 21 forum were consistent with those he has heard in forums on the subject he has attended around the country since the spring of 1997. He added, however, that, in other cities, forum participants displayed a greater acceptance of the overall need to begin tracking new HIV infections, regardless of how that is done. Ward said he believes additional public discussion will help alleviate concerns about how HIV reporting can be done while still protecting privacy rights.

DOH Director Noonan stressed to the forum and to the *Blade* that the department is in only the preliminary stages of discussing an HIV reporting system in D.C. and that DOH is attempting to gather input from the community before moving forward with any plans.▼

by Clint Stelb

Pat Hawkins said Whitman-Walker Clinic is opposed to names reporting and also has concerns about reporting systems that use "unique identifiers."

CDC touts study as definitive word

by Kai Wright

The U.S. Centers for Disease Control and Prevention is citing the results of a new study conducted by researchers at the University of California at San Francisco as proof that reporting to the government the names of people who test positive for HIV does not deter people from voluntarily seeking to be tested.

Surveying a population of people considered among those with a high-risk of becoming infected with HIV in nine states, UCSF researchers found that, of respondents who had *not* taken an HIV antibody test, only 2 percent cited a fear that their names being reported to the government as the primary reason for having not doing so.

The study was designed to address questions which arose during discussions between the CDC and national AIDS policy lobby groups in 1993 about how to best deal with the growing need to track new HIV infections nationally. Concerned about the negative impact that reporting HIV cases could have on the effort to bring people in for HIV testing, the AIDS groups asked the CDC at that time to commission an independent study of possible deterrents to testing, including the impact of a names reporting system.

"This is not a study that says names reporting has no deter-

Continued on page 29

CDC touts study results

Continued from page 10

rent effect at all," cautioned UCSF's Rick Hecht, who directed the study's design and wrote up its results. "On the other hand, I think it helps to put names reporting in perspective."

The study, conducted between December 1995 and December 1996, has not been published yet. According to Hecht, both UCSF and CDC want the study released in a peer-reviewed journal and are waiting to hear from the *Journal of the American Medical Association*. For that reason, Hecht declined to provide to the *Blade* details of the study's findings.

However, in an April 21 public forum held in Washington, D.C., the CDC's director of HIV/AIDS surveillance, Dr. John Ward, defended names reporting by telling the audience about the study and citing the two percent figure as proof that names reporting does not deter people from getting HIV tests. Ward's presentation was met with an uproar from people in the audience who had not heard of the study and demanded to know more about its methodology.

Ward then explained only that the study asked sample populations in nine states several questions to determine what factors have acted as a deterrent to their getting tested. He said that, in addition to the two percent who listed a fear that their names would be reported to the government as their number one concern, another 19 percent listed that concern as one concern among others preventing them from getting tested. He noted that these results cut across racial and ethnic lines.

Hecht confirmed these findings and explained some of the study's methodology. He said that researchers met with community-based organizations in over 30

by Clint Stelb

Daniel Zingale: If there's any disincentive to testing, why not pursue alternatives to names reporting?

cities in nine states to select a sample population of approximately 2,700 total people who either had recently taken an HIV antibody test or had never taken an HIV antibody test. Hecht said researchers paid "some attention to diversity" in selecting the sample population. The community organizations helped researchers locate public gathering places from which to select three categories of high-risk respondents to survey: Gay and bisexual men from Gay nightclubs, people who inject illegal drugs from street-corners, and heterosexual persons visiting clinics for treating sexually transmitted diseases.

Among other questions, the respondents were asked what factors have either prevented them from getting an HIV antibody test or contributed to any delay they may have experienced in getting a test.

by Clint Stelb

"We don't know what that fear is," said Cornelius Baker. "So we need a little more information."

Each respondent was presented with a list of answers, among which, according to the CDC, was that the respondent was "worried that [his or her] name would be reported to the government if [he or she] tested positive." Hecht said that researchers also recorded the racial or ethnic backgrounds of each respondent.

AIDS Action Executive Director Daniel Zingale, who is opposed to names reporting, said he will not comment on the study in detail until he has seen it. But, Zingale said, "It seems to me that if there's *any* evidence in this study that there's an added disincentive to testing, then I can't see why we wouldn't pursue other alternatives to names reporting."

National Association of People With AIDS (NAPWA) Executive Director A. Cornelius Baker said he, too, is eager to see the whole study, but expressed skepticism that it would provide any definitive proof that names reporting does not deter people from getting HIV antibody tests. NAPWA opposes names reporting. Baker co-authored an October *New England Journal of Medicine* article with Ward which presented the case for developing some sort of national system for tracking HIV but stopped short of recommending a system. Baker, who participated in the 1993 discussions which led to the new study, applauded the CDC's willingness to conduct an independent, academic examination of names reporting's potential impact on testing.

"What we do know is that the overwhelming majority of people have said that a general fear delays them from getting tested. We don't know what that fear is," said Baker. "So we need a little more information."

Ward said the new study counters several other studies released in previous years which concluded that names reporting would serve as a deterrent to testing. He argued that this new study stands above others because of the statistically sound manner in which it was.▼

SANDIE MARVEL
June 17, 1958 ~ March 26, 1998

Sandie Marvel p
away five weeks ago
fight to live show
how to be strong.
indomitable spirit
live on in all of us.
smile and wit greet
Street, rain or sh
Peppers front
Sandie told st
laughed, cried, and
our lives. Her frien
miss her dearly.

From WASHINGTON BLADE

HIV debate erupts

Distrust of government underlies emotions at HIV reporting forum

by Kai Wright

In an emotionally charged two-hour public forum April 21, the national controversy over if and how public health officials should track new HIV infections hit Washington, D.C. Approximately 100 people, many representing local community-based AIDS organizations, presented local and national public health officials with a clear consensus: The government cannot be trusted to protect sensitive information identifying people living with HIV, particularly if that information is collected in the form of the names of people with HIV.

One speaker after another approached the forum's panel of public health experts, assembled by the D.C. Department of Health (DOH). Many shared personal anecdotes of having been discriminated against because of his or her HIV-positive status. Many recounted incidents in which government officials failed to protect privacy rights when dealing with non-HIV-related health information. And many argued that any system of reporting people with HIV in the District would serve only to deter at-risk populations from voluntarily seeking out an HIV antibody test. People living with HIV in prisons, senior citizens and young people, women who inject illegal drugs and women who are pregnant, immigrants, and Gay and bisexual men of color were all among the groups represented at the microphone. And all pleaded with DOH Director Allan Noonan not to create an HIV reporting system in the District.

Currently, the Washington, D.C., Department of Health (DOH) keeps records of only people with full-blown AIDS, tracking new cases by recording each person's name. Noonan said the forum marked the beginning of deliberations on whether to develop a system for tracking HIV infection as well.

"The purpose of this meeting was to get [community] input into developing HIV surveillance," Noonan told the *Blade* after the meeting. "This is the beginning of our planning for the future. In order to plan for the future, you first gather information. That's what we're doing here." Whitman-Walker Clinic Deputy Director Pat Hawkins, who sat on the six-member panel of health experts who joined Noonan in addressing the issue, joined the chorus of those in the audience opposing any attempt to develop an HIV reporting system in D.C. Hawkins made the Clinic's stance clear.

"We are opposed to names reporting and, at this point in time, we have serious reservations about 'unique identifiers' as well," Hawkins said, attracting cheers from the audience. "Unique identifier" systems, currently used to count HIV infection cases only by Maryland and Texas, give each individual who tests positive a distinguishing code rather than recording the individual's name.

Hawkins said either system would create "a deterrent to testing." She said that, while city officials could probably be trusted to protect the privacy of persons with HIV and guard

identifying information from being used to discriminate against such persons, "you cannot predict what our Congress will do to us in the District."

In his remarks opening the forum, Noonan told the audience that DOH must balance its competing concerns: the need to get accurate data on HIV infection rates against the need to avoid jeopardizing the privacy of people with HIV or making them vulnerable to anti-HIV discrimination which still exists in the city.

Noonan said this issue has become more pressing as new treatments prolonging the life spans of people with HIV/AIDS have become available and their success in prolonging lives has begun placing new demands on public health officials to find and allocate funding and focus their efforts.

Noonan was joined by the U.S. Centers for Disease Control and Prevention's HIV surveillance branch head Dr. John Ward. Ward co-authored a *New England Journal of Medicine* article last October that fanned the flames of the debate over HIV reporting by laying out the case for developing a national system for tracking HIV infections. The CDC was expected to release a report outlining its recommendations for how such a system should work early this year. But that report is still not out, and Ward declined to predict when it would be. States would not be forced to institute the report's recommendations, but Congress could subsequently condition federal funds for state health programs on compliance with the CDC guidelines.

Currently, every state in the nation has self-imposed requiring health care providers and laboratories to report the names of people diagnosed with full-blown AIDS to state health officials. State officials send these reports, which include a variety of health and demographic information, to the CDC. Information that could identify an individual patient is deleted from the reports sent to the CDC, leaving patient names in the hands of state health officials. The system allows the CDC to develop a national picture of the AIDS epidemic and to direct funding to priority programs.

But no such system exists for tracking the number of people with HIV infection. Currently, according to the CDC, only 28 states, including Virginia, record the names of people with HIV infection. Ward told the April 21 forum, and has argued in similar forums around the country, that the lack of information about the number of HIV cases prevents the CDC from developing a reliable picture of the virus's impact nationally. He said it also makes more difficult CDC's efforts to prevent its spread and focus federal funding on priority programs.

"Our concern is that we are losing our ability to track the HIV epidemic," Ward told the gathering. "AIDS data tells us about treatment ... not about who is getting infected." Ward explained that new treatments forestall the advent of full-blown AIDS for many people with HIV and, thus, that tracking the epidemic from its endpoint is no longer effective.

Debating the numbers on names reporting

In a discussion in which nearly every speaker cited a different study evaluating the effectiveness of a names-based HIV tracking system, Ward cited a new CDC-funded study conducted by

researchers at the University of California at San Francisco. Ward told the gathering that the study, conducted in 1995 and 1996 but, as yet, unpublished, counters other studies that have presented evidence that a names-based HIV tracking system would deter individuals from getting tested. (See related story.) The study found that, of those who had not taken the test, only 2 percent indicated that the primary reason for not doing so was a concern that their names would be reported to the government. He said another 19 percent of those who had not been tested listed that concern as one among others. Ward noted that, among the people who *had* been tested, the percentages were similar. Ward said these results cut across racial and ethnic lines.

But the audience reacted strongly to these findings, interrupting Ward's presentation and demanding to know in which cities the study was conducted and asking for more details about how the sample population was selected. Several individuals shouted Ward down as he attempted to answer those questions, apparently unconvinced that the study's results were valid. One audience member responded to Ward's explanation by asking, sarcastically, if the sample population "included anyone who was sober or awake."

After Ward's presentation, several audience members argued that, regardless of what other studies have found, a names-based reporting system would not work in D.C. La Clinica del Pueblo's Candace Kattar said a names-based reporting system would cripple her organization, which provides counseling and testing for the Latino community. Kattar said that, from January to March, La Clinica informally surveyed people who came in for an HIV test, asking if they would have come if they knew their names would be reported to the government if they tested positive. Kattar said that nearly 85 percent of those that responded said they would not have come in for a test.

"In the population that we serve, there is a serious concern of many people here ... a great fear of the Immigration and Naturalization Service. And they live with that fear," Kattar told DOH officials during the forum's question and answer period. She predicted that the institution of a names-based reporting system would spark a "backlash" among La Clinica's clients, driving many to not only refuse to get HIV tests but also to stop taking advantage of other clinic programs.

Ward said that all the concerns presented during the April 21 forum were consistent with those he has heard in forums on the subject he has attended around the country since the spring of 1997. He added, however, that, in other cities, forum participants displayed a greater acceptance of the overall need to begin tracking new HIV infections, regardless of how that is done. Ward said he believes additional public discussion will help alleviate concerns about how HIV reporting can be done while still protecting privacy rights.

DOH Director Noonan stressed to the forum and to the *Blade* that the department is in only the preliminary stages of discussing an HIV reporting system in D.C. and that DOH is attempting to gather input from the community before moving forward with any plans.

CDC touts study as definitive word

by Kai Wright

The U.S. Centers for Disease Control and Prevention is citing the results of a new study conducted by researchers at the University of California at San Francisco as proof that reporting to the government the names of people who test positive for HIV does not deter people from voluntarily seeking to be tested.

Surveying a population of people considered among those with a high-risk of becoming infected with HIV in nine states, UCSF researchers found that, of respondents who had *not* taken an HIV antibody test, only 2 percent cited a fear that their names being reported to the government as the primary reason for having not doing so.

The study was designed to address questions which arose during discussions between the CDC and national AIDS policy lobby groups in 1993 about how to best deal with the growing need to track new HIV infections nationally. Concerned about the negative impact that reporting HIV cases could have on the effort to bring people in for HIV testing, the AIDS groups asked the CDC at that time to commission an independent study of possible deterrents to testing, including the impact of a names reporting system.

"This is not a study that says names reporting has no deterrent effect at all," cautioned UCSF's Rick Hecht, who directed the study's design and wrote up its results. "On the other hand, I think it helps to put names reporting in perspective."

The study, conducted between December 1995 and December 1996, has not been published yet. According to Hecht, both UCSF and CDC want the study released in a peer-reviewed journal and are waiting to hear from the *Journal of the American Medical Association*. For that reason, Hecht declined to provide to the *Blade* extensive details of the study's findings.

However, in an April 21 public forum held in Washington, D.C., the CDC's director of HIV/AIDS surveillance, Dr. John Ward, defended names reporting by telling the audience about the study and citing the two percent figure as proof that names reporting does not deter people from getting HIV tests. Ward's presentation was met with an uproar from people in the audience who had not heard of the study and demanded to know more about its methodology.

Ward then explained only that the study asked sample populations in nine states several questions to determine what factors have acted as a deterrent to their getting tested. He said that, in addition to the two percent who listed a fear that their names would be reported to the government as their number one concern, another 19 percent listed that concern as one concern among others preventing them from getting tested. He further noted that these results cut across racial and ethnic lines.

Hecht confirmed these findings and explained some of the study's methodology. He said that researchers met with community-based organizations in over 30 cities in nine states to select a sample population of approximately 2,700 total people who either had recently taken an HIV antibody test or had never taken an HIV antibody test. Hecht said researchers paid "some

attention to diversity" in selecting the sample population. The community organizations helped researchers locate public gathering places from which to select three categories of high-risk respondents to survey: Gay and bisexual men from Gay nightclubs, people who inject illegal drugs from street-corners, and heterosexual persons visiting clinics for treating sexually transmitted diseases.

Among other questions, the respondents were asked what factors have either prevented them from getting an HIV antibody test or contributed to any delay they may have experienced in getting a test. Each respondent was presented with a list of answers, among which, according to the CDC, was that the respondent was "worried that [his or her] name would be reported to the government if [he or she] tested positive." Hecht said that researchers also recorded the racial or ethnic backgrounds of each respondent.

AIDS Action Executive Director Daniel Zingale, who is opposed to names reporting, said he will not comment on the study in detail until he has seen it. But, Zingale said, "It seems to me that if there's *any* evidence in this study that there's an added disincentive to testing, then I can't see why we wouldn't pursue other alternatives to names reporting."

National Association of People With AIDS (NAPWA) Executive Director A. Cornelius Baker said he, too, is eager to see the whole study, but expressed skepticism that it would provide any definitive proof that names reporting does not deter people from getting HIV antibody tests. NAPWA opposes names reporting. Baker co-authored an October *New England Journal of Medicine* article with Ward which presented the case for developing some sort of national system for tracking HIV but stopped short of recommending a system. Baker, who participated in the 1993 discussions which led to the new study, applauded the CDC's willingness to conduct an independent, academic examination of names reporting's potential impact on testing.

"What we do know is that the overwhelming majority of people have said that a general fear delays them from getting tested. We don't know what that fear is," said Baker. "So we need a little more information."

Ward said the new study counters several other studies released in previous years which concluded that names reporting would serve as a deterrent to testing. He argued that this new study stands above others because of the statistically sound manner in which it was.

Activists oppose reporting HIV names

State officials insist 'no decision has been made'

by LAURA BROWN

From attorneys and doctors to indigent patients on public assistance, more than 150 people infected or affected by HIV spoke out unanimously at a town hall meeting April 16 against a proposed plan to collect names of HIV-positive Georgians in order to better track the spread of the disease.

Many of those attending the heated town hall meeting returned the next morning, when the Georgia Task Force on AIDS heard testimony on HIV surveillance from the national Centers for Disease Control, area AIDS service providers and the general public. With the exception of the CDC's Dr. John Ward, sentiments again ran unanimously against names reporting.

AIDS advocates suggested, as an alternative to reporting the names of those with HIV, that Georgia consider reporting HIV cases using a "unique identifier" of numbers and letters, similar to systems in use in Texas and Maryland. While Texas officials have criticized their system for incomplete data and are considering moving to names reporting, Maryland is calling their program a guarded success.

SisterLove Executive Director Dazon Dixon and Atlanta attorney Chip Rowan were among those voicing criticism of plans to collect the names of Georgians carrying the HIV virus.

In "UI" systems, a code made up of unchangeable data elements such as a certain letter of a patient's name, a partial social security number, or even a standard hand measurement are compiled to create a unique code for each person who tests positive for HIV.

➢ Continued on Page 19

Georgia Equality Project turns the corner, leaders say

by LAURA BROWN

The Georgia Equality Project Foundation [illegible] steward of the community's money" was one of the chief concerns raised at their last public forum in February.

[illegible] aside 15 percent of monthly income to hire staff or consultants to monitor the 1999 Legislature, but Knox said limited finances

NationsBank employees get partner benefits

The 7,800 Atlantans employed by NationsBank now have the opportunity to buy insurance benefits for same-sex partners, thanks to the Charlotte-based company's planned merger with BankAmerica.

"I think it is a great victory for every gay employee of NationsBank," Jamie Ensley, an openly gay vice president in the Atlanta business banking division, told *Southern Voice*.

"I appreciate [NationsBank CEO] Hugh McColl's stand on this issue, and I really believe that he did this because it was the right thing to do. With the merger, I think we will now be the number one bank in America, and we can be a role model for other banks."

NationsBank's 90,000 employees did not have domestic partner benefits before the merger, although spokesperson Lisa Lester said the company has been "really proud of our diversity and always striving to do better."

NationsBank

"It's a historic merger, and the new corporation will offer these benefits," said Shelly Schoenfeld, a NationsBank assistant vice president in Charlotte. "I appreciate [NationsBank's] stance on this issue, and I know a lot of other gay

Reporting HIV names

➢ Continued from Page 7

Public health officials can then monitor the spread of HIV in order to target prevention and services, while those tested can feel more secure because "their names won't be on any list," UI supporters said.

Dr. Melanie Thompson, principal researcher for the AIDS Research Consortium of Atlanta, AIDS Survival Project Executive Director Jeff Graham, SisterLove founder Dazon Dixon, AID Atlanta's Craig Washington and civil rights attorney Chip Rowan were among the community leaders who said they oppose names reporting. Still, each speaker offered only a personal viewpoint; none spoke on behalf of AIDS service organizations.

Neither the Task Force nor the Georgia Department of Human Resources has made a decision about what form of HIV surveillance to conduct, officials stressed. DHR's David Johnson said the agency will conduct public hearings in all 19 Georgia health districts before October and will take at least a year to reach a final decision.

"The one thing I want you to hear is we have not made a decision yet, and we will not make a decision in a vacuum," he promised. "We want buy-in from the entire community, and if we don't have that, we all lose."

Although all 50 states currently monitor cases of full-blown AIDS using names, that information is kept on the state level and only statistics are tracked nationally.

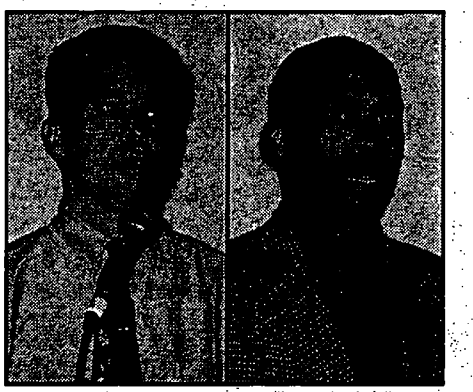
Opponents to HIV-names reporting said they fear the program would deter testing, and it could be vulnerable to both illegal and legal confidentiality breaches.

More disturbing than the possibility that someone could violate policy and "leak the list," they said, is the fear that increasingly conservative state legislatures could repeal confidentiality laws that would protect HIV-positive people from exposure.

"I can say sincerely that I believe the DHR has people's best interests at heart, but I don't trust the legislature," ASP's Graham said. "To over-generalize the Georgia legislature, they never cared about HIV at all, they hate gay men, they've never cared much for people of color, and if you are an IV drug user, you deserve to die."

According to Anna Forbes, a consultant and UI researcher who spoke at the town hall meeting, in 1991 the Illinois legislature passed a law requiring its health department to identify HIV-positive health care providers by cross-matching the state AIDS registry with licensing records.

The law further required the department to contact all the HIV-positive providers' patients, Forbes said, but community pressure kept it from being funded and therefore implemented.



The CDC's John Ward (left) defended plans to report the names of Georgians with HIV, but state official David Johnson promised that his agency had made no final decision.

UI proponents said they fear even more widespread misuse of HIV-lists, and cited criminal prosecutions as another area for potential problems. As states move to criminalize exposing a sex partner to HIV infection as attempted murder, they asked, what will keep prosecutors from getting subpoenas to see if defendants' names are on the HIV registry?

"The only safe list is the list that is never created," Forbes concluded, drawing applause from forum attendees.

In favor of names reporting, meanwhile, the CDC's Ward said the system has less chance for duplication or incomplete data then constructing a UI code, and will be easier to implement because health care providers are already accustomed to keeping other medical records using names.

NationsBank

➢ Continued from Page 7

realization that the dependents our employees support might be parents, siblings or domestic partners."

BankAmerica's equal employment opportunity policy also protects gay employees from being fired, denied a promotion or harassed just because of their sexual orientation.

NationsBank, however, does not include sexual orientation in its non-discrimination policy, and it remains unclear how it will be affected by the merger. "That issue has not been addressed," Waller said.

McColl said that employees will not lose any benefits they now get, and NationsBank workers could gain unspecified ones from the merger.

"Bank of America has many very positive, forward-thinking policies... and basically we'll probably extend them across the franchise after we study everything," he said.

In 1990, only a half-dozen employers offered health and other benefits to same-sex couples. According to the Human Rights Campaign, nearly 500 employers now offer domestic partnership.

Turner Broadcasting Systems, Inc., and Emory University are among the large Atlanta employers offering the benefits.

—From staff writer Laura Brown and wire reports

The Washington Blade

SERVING THE NATION'S CAPITAL SINCE 1969

HIV debate erupts

Distrust of government underlies emotions at HIV reporting forum

by Clint Steib

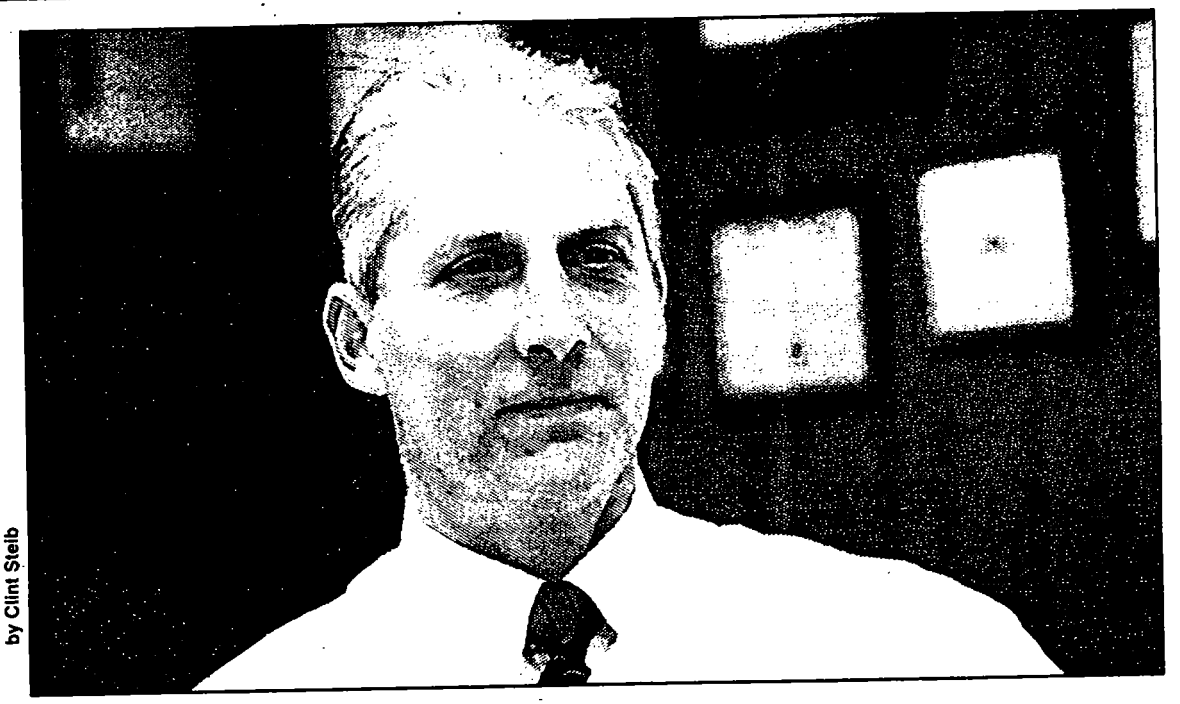
"The purpose of this meeting was to get [community] input into developing HIV surveillance," said Allan Noonan.

by Kai Wright

In an emotionally charged two-hour public forum April 21, the national controversy over if and how public health officials should track new HIV infections hit Washington, D.C. Approximately 100 people, many representing local community-based AIDS organizations, presented local and national public health officials with a clear consensus: The government cannot be trusted to protect sensitive information identifying people living with HIV, particularly if that information is collected in the form of the names of people with HIV.

One speaker after another approached the forum's panel of public health experts, assembled by the D.C. Department of Health (DOH). Many shared personal anecdotes of having been discriminated against because of his or her HIV-positive status. Many recounted incidents in which government officials failed to protect privacy rights when dealing with non-HIV-related health information. And

Continued on page 10



by Clint Steib

Crime solvers

D.C detectives team up to solve Gay murders

by Lou Chibbaro Jr.

A newly created team of D.C. Police homicide detectives will act as specialists in cases involving the murders of Gay men and Lesbians, and the team will take unprecedented steps to reach out to the Gay community for help in solving these cases, the commander of the homicide squad said this week.

Homicide Commander Ross Swope said he

by Clint Steib

eaders p Foru

HIV reporting debate erupts in D.C.

Continued from page 1

many argued that any system of reporting people with HIV in the District would serve only to deter at-risk populations from voluntarily seeking out an HIV antibody test. People living with HIV in prisons, senior citizens and young people, women who inject illegal drugs and women who are pregnant, immigrants, and Gay and bisexual men of color were all among the groups represented at the microphone. And all pleaded with DOH Director Allan Noonan not to create an HIV reporting system in the District.

Currently, the Washington, D.C., Department of Health (DOH) keeps records of only people with full-blown AIDS, tracking new cases by recording each person's name. Noonan said the forum marked the beginning of deliberations on whether to develop a system for tracking HIV infection as well.

"The purpose of this meeting was to get [community] input into developing HIV surveillance," Noonan told the *Blade* after the meeting. "This is the beginning of our planning for the future. In order to plan for the future, you first gather information. That's what we're doing here."

Whitman-Walker Clinic Deputy Director Pat Hawkins, who sat on the six-member panel of health experts who joined Noonan in addressing the issue, joined the chorus of those in the audience opposing any attempt to develop an HIV reporting system in D.C. Hawkins made the Clinic's stance clear.

"We are opposed to names reporting and, at this point in time, we have serious reservations about 'unique identifiers' as well," Hawkins said, attracting cheers from the audience. "Unique identifier" systems, currently used to count HIV infection cases only by Maryland and Texas, give each individual who tests positive a distinguishing code rather than recording the individual's name.

Hawkins said either system would create "a deterrent to testing." She said that, while city officials could probably be trusted to protect the privacy of persons with HIV and guard information from being used to discriminate against such persons, "you cannot predict what our Congress will do to us in the District."

In his remarks opening the forum, Noonan told the audience that DOH must balance its competing concerns: the need to get accurate data on HIV infection rates against the need to avoid jeopardizing the privacy of people with HIV or making them vulnerable to anti-HIV discrimination which still exists in the city.

Noonan said this issue has become more pressing as new treatments prolonging the life spans of people with HIV/AIDS have become available and their success in prolonging lives has begun placing new demands on public health officials to find and allocate funding and focus their efforts.

Noonan was joined by the U.S. Centers for Disease Control and Prevention's HIV surveillance branch head Dr. John Ward. Ward co-authored a *New England Journal of Medicine* article last October that fanned the flames of the debate over HIV reporting by laying out the case for developing a national system for tracking HIV infections. The CDC was expected to release a report outlining its recommendations for how such a system should work early this year. But that report is still not out, and Ward declined to predict when it would be. States would not be forced to institute the recommendations, but Congress could subsequently condition federal funds for state health programs on compliance with the CDC guidelines.

Currently, every state in the nation has self-imposed requiring health care providers and laboratories to report the names of people diagnosed with full-blown AIDS to state health officials. State officials send these reports, which include a variety of health and demographic information, to the CDC. Information that could identify an individual patient is deleted from the reports sent to the CDC, leaving patient names in the hands of state health officials. The system allows the CDC to develop a national picture of the AIDS epidemic and to direct funding to priority programs.

But no such system exists for tracking the number of people with HIV infection. Currently, according to the CDC, only 28 states, including Virginia, record the names of people with HIV infection. Ward told the April 21 forum, and has argued in similar forums around the country, that the lack of information about the number of HIV cases prevents the CDC from developing a reliable picture of the virus's impact nationally. He said it also makes more difficult CDC's efforts to prevent its spread and focus federal funding on priority programs.

"Our concern is that we are losing our ability to track the HIV epidemic," Ward told the gathering. "AIDS data tells us about treatment ... not about who is getting infected." Ward explained that new treatments forestall the advent of full-blown AIDS for many people with HIV and, thus, that tracking the epidemic from its endpoint is no longer effective.

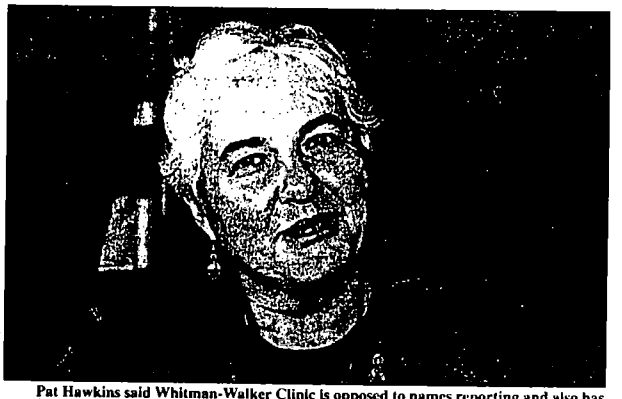
Debating the numbers

In a discussion in which nearly every speaker cited a different study evaluating the effectiveness of a names-based HIV tracking system, Ward cited a new CDC-funded study conducted by researchers at the University of California at San Francisco. Ward told the gathering that the study, conducted in 1995 and 1996 but, as yet, unpublished, counters other studies that have presented evidence that a names-based HIV tracking system would deter individuals from getting tested. (See related story.) The study found that, of those who had not taken the test, only 2 percent indicated that the primary reason for not doing so was a concern that their names would be reported to the government. He said another 19 percent of those who had not been tested listed that concern as one among others. Ward noted that, among the people who *had* been tested, the percentages were similar. Ward said these results cut across racial and ethnic lines.

But the audience reacted strongly to these findings, interrupting Ward's presentation and demanding to know in which cities the study was conducted and asking for more details about how the sample population was selected. Several individuals shouted Ward down as he attempted to answer those questions, apparently unconvinced that the study's results were valid. One audience member responded to Ward's explanation by asking, sarcastically, if the sample population "included anyone who was sober or awake."

After Ward's presentation, several audience members argued that, regardless of what other studies have found, a names-based reporting system would not work in D.C. La Clinica del Pueblo's Candace Kattar said a names-based reporting system would cripple her organization, which provides counseling and testing for the Latino community. Kattar said that, from January to March, La Clinica informally surveyed people who came in for an HIV test, asking if they would have come if they knew their names would be reported to the government if they tested positive. Kattar said that nearly 85 percent of those that responded said they would not have come in for a test.

"In the population that we serve, there is a serious concern of many people here ... a great fear of the Immigration and Naturalization Service. And they live with that fear," Kattar told DOH officials during the forum's question and answer period. She predicted that the institution of a names-based reporting system would spark a "backlash" among La Clinica's clients, driving many to not only refuse to get HIV tests but also to stop taking advantage of other clinic programs.



by Clint Stelb

Pat Hawkins said Whitman-Walker Clinic is opposed to names reporting and also has concerns about reporting systems that use "unique identifiers."

Ward said that all the concerns presented during the April 21 forum were consistent with those he has heard in forums on the subject he has attended around the country since the spring of 1997. He added, however, that, in other cities, forum participants displayed a greater acceptance of the overall need to begin tracking new HIV infections, regardless of how that is done. Ward said he believes additional public discussion will help alleviate concerns about how HIV reporting can be done while still protecting privacy rights.

DOH Director Noonan stressed to the forum and to the *Blade* that the department is in only the preliminary stages of discussing an HIV reporting system in D.C. and that DOH is attempting to gather input from the community before moving forward with any plans.▼

CDC touts study as definitive word

by Kai Wright

The U.S. Centers for Disease Control and Prevention is citing the results of a new study conducted by researchers at the University of California at San Francisco as proof that reporting to the government the names of people who test positive for HIV does not deter people from voluntarily seeking to be tested.

Surveying a population of people considered among those with a high-risk of becoming infected with HIV in nine states, UCSF researchers found that, of respondents who had *not* taken an HIV antibody test, only 2 percent cited a fear that their names being reported to the government as the primary reason for having not doing so.

The study was designed to address questions which arose during discussions between the CDC and national AIDS policy lobby groups in 1993 about how to best deal with the growing need to track new HIV infections nationally. Concerned about the negative impact that reporting HIV cases could have on the effort to bring people in for HIV testing, the AIDS groups asked the CDC at that time to commission an independent study of possible deterrents to testing, including the impact of a names reporting system.

"This is not a study that says names reporting has no deter-

Continued on page 29

CDC touts study results

Continued from page 10

rent effect at all," cautioned UCSF's Rick Hecht, who directed the study's design and wrote up its results. "On the other hand, I think it helps to put names reporting in perspective."

The study, conducted between December 1995 and December 1996, has not been published yet. According to Hecht, both UCSF and CDC want the study released in a peer-reviewed journal and are waiting to hear from the *Journal of the American Medical Association*. For that reason, Hecht declined to provide to the *Blade* details of the study's findings.

However, in an April 21 public forum held in Washington, D.C., the CDC's director of HIV/AIDS surveillance, Dr. John Ward, defended names reporting by telling the audience about the study and citing the two percent figure as proof that names reporting does not deter people from getting HIV tests. Ward's presentation was met with an uproar from people in the audience who had not heard of the study and demanded to know more about its methodology.

Ward then explained only that the study asked sample populations in nine states several questions to determine what factors have acted as a deterrent to their getting tested. He said that, in addition to the two percent who listed a fear that their names would be reported to the government as their number one concern, another 19 percent listed that concern as one concern among others preventing them from getting tested. He noted that these results cut across racial and ethnic lines.

Hecht confirmed these findings and explained some of the study's methodology. He said that researchers met with community-based organizations in over 30

by Clint Stelb

Daniel Zingale: If there's any disincentive to testing, why not pursue alternatives to names reporting?

cities in nine states to select a sample population of approximately 2,700 total people who either had recently taken an HIV antibody test or had never taken an HIV antibody test. Hecht said researchers paid "some attention to diversity" in selecting the sample population. The community organizations helped researchers locate public gathering places from which to select three categories of high-risk respondents to survey: Gay and bisexual men from Gay nightclubs, people who inject illegal drugs from street-corners, and heterosexual persons visiting clinics for treating sexually transmitted diseases.

Among other questions, the respondents were asked what factors have either prevented them from getting an HIV antibody test or contributed to any delay they may have experienced in getting a test.

by Clint Stelb

"We don't know what that fear is," said Cornelius Baker. "So we need a little more information."

Each respondent was presented with a list of answers, among which, according to the CDC, was that the respondent was "worried that [his or her] name would be reported to the government if [he or she] tested positive." Hecht said that researchers also recorded the racial or ethnic backgrounds of each respondent.

AIDS Action Executive Director Daniel Zingale, who is opposed to names reporting, said he will not comment on the study in detail until he has seen it. But, Zingale said, "It seems to me that if there's *any* evidence in this study that there's an added disincentive to testing, then I can't see why we wouldn't pursue other alternatives to names reporting."

National Association of People With AIDS (NAPWA) Executive Director A. Cornelius Baker said he, too, is eager to see the whole study, but expressed skepticism that it would provide any definitive proof that names reporting does not deter people from getting HIV antibody tests. NAPWA opposes names reporting. Baker co-authored an October *New England Journal of Medicine* article with Ward which presented the case for developing some sort of national system for tracking HIV but stopped short of recommending a system. Baker, who participated in the 1993 discussions which led to the new study, applauded the CDC's willingness to conduct an independent, academic examination of names reporting's potential impact on testing.

"What we do know is that the overwhelming majority of people have said that a general fear delays them from getting tested. We don't know what that fear is," said Baker. "So we need a little more information."

Ward said the new study counters several other studies released in previous years which concluded that names reporting would serve as a deterrent to testing. He argued that this new study stands above others because of the statistically sound manner in which it was.▼

SANDIE MARVEL
June 17, 1958 ~ March 26, 1998

Sandie Marvel pa
away five weeks ago
fight to live showe
how to be strong.
indomitable spirit
live on in all of us.
smile and wit greete
Street, rain or shi
Peppers front
Sandie told st
laughed, cried, and
our lives. Her frien
miss her dearly.

From WASHINGTON BLADE

HIV debate erupts

Distrust of government underlies emotions at HIV reporting forum

by Kai Wright

In an emotionally charged two-hour public forum April 21, the national controversy over if and how public health officials should track new HIV infections hit Washington, D.C. Approximately 100 people, many representing local community-based AIDS organizations, presented local and national public health officials with a clear consensus: The government cannot be trusted to protect sensitive information identifying people living with HIV, particularly if that information is collected in the form of the names of people with HIV.

One speaker after another approached the forum's panel of public health experts, assembled by the D.C. Department of Health (DOH). Many shared personal anecdotes of having been discriminated against because of his or her HIV-positive status. Many recounted incidents in which government officials failed to protect privacy rights when dealing with non-HIV-related health information. And many argued that any system of reporting people with HIV in the District would serve only to deter at-risk populations from voluntarily seeking out an HIV antibody test. People living with HIV in prisons, senior citizens and young people, women who inject illegal drugs and women who are pregnant, immigrants, and Gay and bisexual men of color were all among the groups represented at the microphone. And all pleaded with DOH Director Allan Noonan not to create an HIV reporting system in the District.

Currently, the Washington, D.C., Department of Health (DOH) keeps records of only people with full-blown AIDS, tracking new cases by recording each person's name. Noonan said the forum marked the beginning of deliberations on whether to develop a system for tracking HIV infection as well.

"The purpose of this meeting was to get [community] input into developing HIV surveillance," Noonan told the *Blade* after the meeting. "This is the beginning of our planning for the future. In order to plan for the future, you first gather information. That's what we're doing here." Whitman-Walker Clinic Deputy Director Pat Hawkins, who sat on the six-member panel of health experts who joined Noonan in addressing the issue, joined the chorus of those in the audience opposing any attempt to develop an HIV reporting system in D.C. Hawkins made the Clinic's stance clear.

"We are opposed to names reporting and, at this point in time, we have serious reservations about 'unique identifiers' as well," Hawkins said, attracting cheers from the audience. "Unique identifier" systems, currently used to count HIV infection cases only by Maryland and Texas, give each individual who tests positive a distinguishing code rather than recording the individual's name.

Hawkins said either system would create "a deterrent to testing." She said that, while city officials could probably be trusted to protect the privacy of persons with HIV and guard

identifying information from being used to discriminate against such persons, "you cannot predict what our Congress will do to us in the District."

In his remarks opening the forum, Noonan told the audience that DOH must balance its competing concerns: the need to get accurate data on HIV infection rates against the need to avoid jeopardizing the privacy of people with HIV or making them vulnerable to anti-HIV discrimination which still exists in the city.

Noonan said this issue has become more pressing as new treatments prolonging the life spans of people with HIV/AIDS have become available and their success in prolonging lives has begun placing new demands on public health officials to find and allocate funding and focus their efforts.

Noonan was joined by the U.S. Centers for Disease Control and Prevention's HIV surveillance branch head Dr. John Ward. Ward co-authored a *New England Journal of Medicine* article last October that fanned the flames of the debate over HIV reporting by laying out the case for developing a national system for tracking HIV infections. The CDC was expected to release a report outlining its recommendations for how such a system should work early this year. But that report is still not out, and Ward declined to predict when it would be. States would not be forced to institute the report's recommendations, but Congress could subsequently condition federal funds for state health programs on compliance with the CDC guidelines.

Currently, every state in the nation has self-imposed requiring health care providers and laboratories to report the names of people diagnosed with full-blown AIDS to state health officials. State officials send these reports, which include a variety of health and demographic information, to the CDC. Information that could identify an individual patient is deleted from the reports sent to the CDC, leaving patient names in the hands of state health officials. The system allows the CDC to develop a national picture of the AIDS epidemic and to direct funding to priority programs.

But no such system exists for tracking the number of people with HIV infection. Currently, according to the CDC, only 28 states, including Virginia, record the names of people with HIV infection. Ward told the April 21 forum, and has argued in similar forums around the country, that the lack of information about the number of HIV cases prevents the CDC from developing a reliable picture of the virus's impact nationally. He said it also makes more difficult CDC's efforts to prevent its spread and focus federal funding on priority programs.

"Our concern is that we are losing our ability to track the HIV epidemic," Ward told the gathering. "AIDS data tells us about treatment ... not about who is getting infected." Ward explained that new treatments forestall the advent of full-blown AIDS for many people with HIV and, thus, that tracking the epidemic from its endpoint is no longer effective.

Debating the numbers on names reporting

In a discussion in which nearly every speaker cited a different study evaluating the effectiveness of a names-based HIV tracking system, Ward cited a new CDC-funded study conducted by

researchers at the University of California at San Francisco. Ward told the gathering that the study, conducted in 1995 and 1996 but, as yet, unpublished, counters other studies that have presented evidence that a names-based HIV tracking system would deter individuals from getting tested. (See related story.) The study found that, of those who had not taken the test, only 2 percent indicated that the primary reason for not doing so was a concern that their names would be reported to the government. He said another 19 percent of those who had not been tested listed that concern as one among others. Ward noted that, among the people who *had* been tested, the percentages were similar. Ward said these results cut across racial and ethnic lines.

But the audience reacted strongly to these findings, interrupting Ward's presentation and demanding to know in which cities the study was conducted and asking for more details about how the sample population was selected. Several individuals shouted Ward down as he attempted to answer those questions, apparently unconvinced that the study's results were valid. One audience member responded to Ward's explanation by asking, sarcastically, if the sample population "included anyone who was sober or awake."

After Ward's presentation, several audience members argued that, regardless of what other studies have found, a names-based reporting system would not work in D.C. La Clinica del Pueblo's Candace Kattar said a names-based reporting system would cripple her organization, which provides counseling and testing for the Latino community. Kattar said that, from January to March, La Clinica informally surveyed people who came in for an HIV test, asking if they would have come if they knew their names would be reported to the government if they tested positive. Kattar said that nearly 85 percent of those that responded said they would not have come in for a test.

"In the population that we serve, there is a serious concern of many people here ... a great fear of the Immigration and Naturalization Service. And they live with that fear," Kattar told DOH officials during the forum's question and answer period. She predicted that the institution of a names-based reporting system would spark a "backlash" among La Clinica's clients, driving many to not only refuse to get HIV tests but also to stop taking advantage of other clinic programs.

Ward said that all the concerns presented during the April 21 forum were consistent with those he has heard in forums on the subject he has attended around the country since the spring of 1997. He added, however, that, in other cities, forum participants displayed a greater acceptance of the overall need to begin tracking new HIV infections, regardless of how that is done. Ward said he believes additional public discussion will help alleviate concerns about how HIV reporting can be done while still protecting privacy rights.

DOH Director Noonan stressed to the forum and to the *Blade* that the department is in only the preliminary stages of discussing an HIV reporting system in D.C. and that DOH is attempting to gather input from the community before moving forward with any plans.

CDC touts study as definitive word

by Kai Wright

The U.S. Centers for Disease Control and Prevention is citing the results of a new study conducted by researchers at the University of California at San Francisco as proof that reporting to the government the names of people who test positive for HIV does not deter people from voluntarily seeking to be tested.

Surveying a population of people considered among those with a high-risk of becoming infected with HIV in nine states, UCSF researchers found that, of respondents who had *not* taken an HIV antibody test, only 2 percent cited a fear that their names being reported to the government as the primary reason for having not doing so.

The study was designed to address questions which arose during discussions between the CDC and national AIDS policy lobby groups in 1993 about how to best deal with the growing need to track new HIV infections nationally. Concerned about the negative impact that reporting HIV cases could have on the effort to bring people in for HIV testing, the AIDS groups asked the CDC at that time to commission an independent study of possible deterrents to testing, including the impact of a names reporting system.

"This is not a study that says names reporting has no deterrent effect at all," cautioned UCSF's Rick Hecht, who directed the study's design and wrote up its results. "On the other hand, I think it helps to put names reporting in perspective."

The study, conducted between December 1995 and December 1996, has not been published yet. According to Hecht, both UCSF and CDC want the study released in a peer-reviewed journal and are waiting to hear from the *Journal of the American Medical Association*. For that reason, Hecht declined to provide to the *Blade* extensive details of the study's findings.

However, in an April 21 public forum held in Washington, D.C., the CDC's director of HIV/AIDS surveillance, Dr. John Ward, defended names reporting by telling the audience about the study and citing the two percent figure as proof that names reporting does not deter people from getting HIV tests. Ward's presentation was met with an uproar from people in the audience who had not heard of the study and demanded to know more about its methodology.

Ward then explained only that the study asked sample populations in nine states several questions to determine what factors have acted as a deterrent to their getting tested. He said that, in addition to the two percent who listed a fear that their names would be reported to the government as their number one concern, another 19 percent listed that concern as one concern among others preventing them from getting tested. He further noted that these results cut across racial and ethnic lines.

Hecht confirmed these findings and explained some of the study's methodology. He said that researchers met with community-based organizations in over 30 cities in nine states to select a sample population of approximately 2,700 total people who either had recently taken an HIV antibody test or had never taken an HIV antibody test. Hecht said researchers paid "some

attention to diversity" in selecting the sample population. The community organizations helped researchers locate public gathering places from which to select three categories of high-risk respondents to survey: Gay and bisexual men from Gay nightclubs, people who inject illegal drugs from street-corners, and heterosexual persons visiting clinics for treating sexually transmitted diseases.

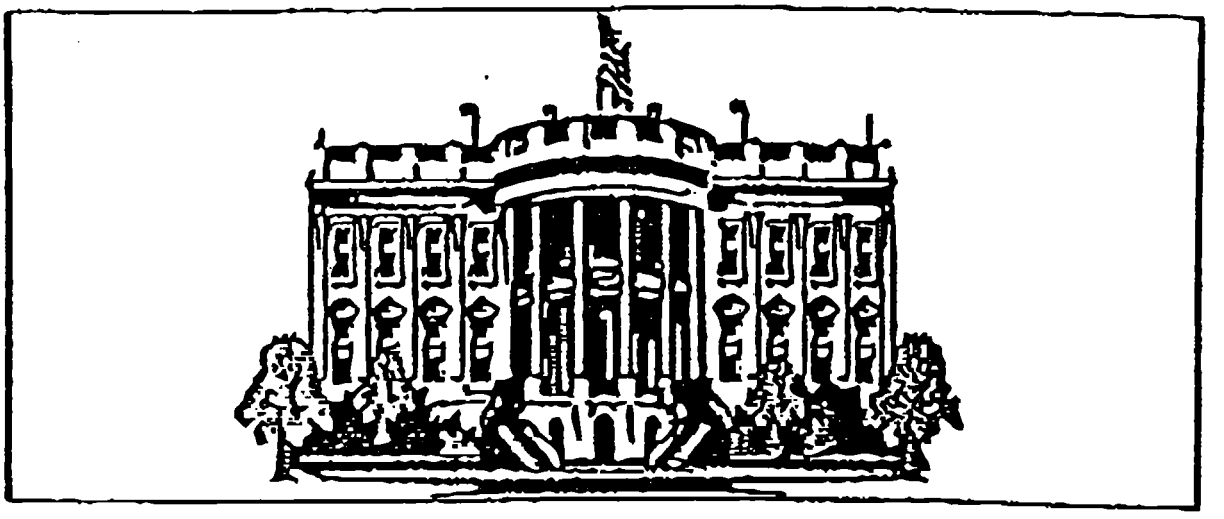
Among other questions, the respondents were asked what factors have either prevented them from getting an HIV antibody test or contributed to any delay they may have experienced in getting a test. Each respondent was presented with a list of answers, among which, according to the CDC, was that the respondent was "worried that [his or her] name would be reported to the government if [he or she] tested positive." Hecht said that researchers also recorded the racial or ethnic backgrounds of each respondent.

AIDS Action Executive Director Daniel Zingale, who is opposed to names reporting, said he will not comment on the study in detail until he has seen it. But, Zingale said, "It seems to me that if there's *any* evidence in this study that there's an added disincentive to testing, then I can't see why we wouldn't pursue other alternatives to names reporting."

National Association of People With AIDS (NAPWA) Executive Director A. Cornelius Baker said he, too, is eager to see the whole study, but expressed skepticism that it would provide any definitive proof that names reporting does not deter people from getting HIV antibody tests. NAPWA opposes names reporting. Baker co-authored an October *New England Journal of Medicine* article with Ward which presented the case for developing some sort of national system for tracking HIV but stopped short of recommending a system. Baker, who participated in the 1993 discussions which led to the new study, applauded the CDC's willingness to conduct an independent, academic examination of names reporting's potential impact on testing.

"What we do know is that the overwhelming majority of people have said that a general fear delays them from getting tested. We don't know what that fear is," said Baker. "So we need a little more information."

Ward said the new study counters several other studies released in previous years which concluded that names reporting would serve as a deterrent to testing. He argued that this new study stands above others because of the statistically sound manner in which it was.



THE WHITE HOUSE
OFFICE OF PRESIDENTIAL PERSONNEL
153 OLD EXECUTIVE OFFICE BUILDING
WASHINGTON, DC 20500
Tel: 202-456-7103
Fax: 202-456-2259

FROM: Joel Ginsberg
Search Manager

DATE : 5/5/98

TO: Sandy Thurman

FAX: 6-2438

TOTAL NUMBER OF PAGES INCLUDING COVER SHEET: 4

COMMENTS: Resumes you requested will follow. Please hold close.

IF THERE ARE ANY PROBLEMS WITH THIS FAX TRANSMISSION, PLEASE CONTACT THE SENDER AT THE TELEPHONE NUMBER LISTED ABOVE. THANK YOU.

NORA
NATIONAL ORGANIZATIONS RESPONDING TO AIDS

HIV Surveillance Paper

Purpose:
This paper is meant to serve as a tool to facilitate and inform community discussion as well as to offer important background information to ground the dialogue regarding expanding the manner in which we do national HIV/AIDS surveillance activities.

Discussion:
There are two questions that frame consideration of incorporating HIV infection reporting as part of our national HIV/AIDS surveillance system. These two questions are:

1. How do we improve and expand our nation's surveillance system to better describe the varying nature of their HIV/AIDS epidemic in the United States? and
2. How do we protect the privacy and confidentiality of individuals living with HIV disease within our nation's surveillance efforts?

Definition:
In public health, *surveillance* is the system that allows for public health jurisdictions (national, regional, state and local) to rapidly monitor, assess and respond to present and emerging health crises in a systematized, organized and scientifically-based manner.

Surveillance systems consist of several different types of activities: sentinel studies, case counting (number of individuals living or deceased who have said disease); incidence and prevalence studies (density of disease and breadth of disease); and even behavioral (risk-taking) surveillance. The more comprehensive the system, the better and more relevant the resulting data.

Background:

- The federal government does not require that any one disease be reported to either itself or to the state. That decision is made by state law, state by state.
- The Centers for Disease Control and Prevention (CDC) does not mandate the implementation of any one system of surveillance (either AIDS or HIV). This decision is made by each state. with funding from the CDC through a Cooperative Agreement (for Surveillance and Epidemiology activities). This Cooperative agreement is separate and distinct from the Cooperative Agreement under the purview of HIV Prevention Community Planning.
- The Council of State and Territorial Epidemiologists (CSTE) establishes a list of nationally recommended reportable diseases and conditions. Recently, CSTE issued the following as part of a larger position paper on surveillance stating: "States should implement confidential HIV infection reporting by name." However, the decision to require or not require such reporting is made by each individual state based on considerations such as available resources for surveillance, patient care, counseling, and the degree to which state laws protect confidentiality.
- All states require AIDS case reporting by name. Currently, 28 states require confidential HIV name reporting by name for both adult/adolescent cases and pediatric cases. By January 1998, New Mexico will implement HIV name reporting systems. Florida implemented HIV named reporting on July 1, 1997 after having suspended their process due to the breach in confidentiality in St. Petersburg. Texas and Maryland, have a unique identifier systems in place for HIV case reporting, although Texas is soon replacing this system with HIV name reporting.
- The CDC has established cooperative agreements with the 65 jurisdictions (the 50 states, the U.S. territories, Puerto Rico, the District of Columbia, and the six Cooperative Agreement Cities -- New York City, Los Angeles, San Francisco, Philadelphia, Houston and Chicago) which, through a Supplemental Guidance issued in January 1994, are responsible for the implementation of HIV Prevention Community Planning.
- In the HIV Prevention Cooperative Agreement with States and Local Health Departments (under the purview of HIV Prevention Community Planning groups), the CDC strongly encourages anonymous HIV antibody testing services. In addition to community planning, CDC provides funds for health departments to fund certain elements of a comprehensive HIV prevention program including Counseling, Testing, Referral and Partner Notification programs (CTRPN), Health Education/Risk Reduction programs (HE/RR) and Public Information.
- The CDC can not currently require specific types of services/programs within these broad components of the HIV Prevention Cooperative Agreement to the jurisdictions (unless through Congressional directive, i.e. report language or law).

NORA
A coalition convened by AIDS Action Council
1875 Connecticut Ave., NW
Suite 700
Washington, DC 20009
202 986 1300
202 986 1345 fax

Challenges:
Recent and compelling data surrounding triple combination therapy has moved states, localities, the federal government to rethink the national standard for sound, timely and relevant surveillance data throughout the continuum of HIV disease. Since new treatments are delaying progression to AIDS (and therefore clinical diagnosis and case reporting processes). This means that AIDS case surveillance systems begin to represent smaller and smaller representative samples of the HIV epidemic in the United States.

In their February 1997 *MMWR* (*Morbidity and Mortality Weekly Report*) and then again in July 1997, the CDC reported a decline in AIDS deaths (although not equally distributed across all populations across the US). These reports have reinforced the discussion as to the manner in which and the extent to which we are gathering more relevant data on the front end of the epidemic (as opposed to the latter end of the epidemic, namely when jurisdictions employ AIDS case surveillance).

The May 1997 CDC consultation meeting in Atlanta on the "Future of Surveillance" raised many questions. While consensus appeared to emerge regarding the need to more effectively monitor the "front-end" of the epidemic, many concerns and even some opposition remained regarding CDC's apparent position encouraging a national HIV surveillance system with named reporting implemented in every jurisdiction

This concern is exacerbated by the Coburn HIV Prevention Act of 1997 which would mandate a national system of HIV named reporting including the portability of names from one state to another and an explicit coupling of partner notification with name-based surveillance. This bill also mandates the creation of a federal name-based registry of all Americans with HIV/AIDS.

The environment created by the introduction of this hostile legislation poses challenges to those wishing to engage in a constructive discussion of HIV surveillance systems. Furthermore, the Coburn legislation, with a "one-size-fits-all" approach to public health crises, threatens our nation's ability to evaluate, by disease and by jurisdiction, the most effective and appropriate surveillance and prevention systems.

Prior to CSTE's new policy on HIV surveillance (June 1997), their position was more flexible, recommending that each state public health agency consider instituting required reporting of HIV infection. Now, encouragement language is more directive. That the CDC will disseminate CSTE's list and policy recommendations, there could be repercussions in jurisdictions not currently engaged in HIV case reporting.

Community members are by no means united in their opinion as to how HIV/AIDS surveillance should occur. There is no current consensus on shifting the paradigm from AIDS case reporting toward HIV reporting. However, it is accurate to state that there is a great deal of fear and apprehension on the part of many advocates and many communities. Institutionalized racism, sexism and homophobia inform community fears about breaches in confidentiality, violence and punitive legal/legislative actions that could result from HIV named reporting.

Currently, AIDS case counts are the basis for resource allocation for significant portions of Titles I and II of the Ryan White CARE Act. While no official formula is used in HIV Prevention Cooperative Agreements for HIV Prevention Community Planning, AIDS case counts are the basis for base funding levels in all 65 jurisdictions. It is important to note that STATUTORY changes would have to be enacted to change the kind of data used as the basis for resource allocation for the CARE Act from AIDS cases to HIV cases. A national HIV surveillance system will not, in and of itself, change resource allocation.

Lastly, there is still a lack of comprehensive federal legislation that protects the privacy and confidentiality of an individual's individually identifiable health information as well as that which protects individuals from discrimination based on real or perceived health and/or genetic status. Two separate Federal District Courts have rendered contradictory rulings on the application of the Americans with Disabilities Act (ADA) and an Appellate Court in New York came to the same conclusion as the U.S. 1st Circuit that HIV disease, absent symptoms, was not considered a disability and therefore was beyond the scope of ADA.

Recently, in response to the Kassebaum/Kennedy Health Insurance Portability and Accountability Act (PL. 104-191), the US Department of Health and Human Services has begun considering processes to address provisions in this law that specifically address privacy and confidentiality. However, preliminary comments from the Clinton Administration have been troubling and incomplete. In other words, neither ADA nor HIPAA have adequate protections in place to protect an individual's privacy of his/her medical records (and therefore name and antibody status) outside of the enforceable provisions of the ADA.

Document prepared by: NORA HIV Prevention Work Group

AIDS ACTION RESOLUTION IN SUPPORT OF HIV REPORTING BY UNIQUE IDENTIFIER AND OTHER NON NAME-BASED SURVEILLANCE SYSTEMS

WHEREAS, AIDS surveillance and AIDS case reporting do not provide an accurate view of the extent of the epidemic nor give a timely and complete indication of trends in the epidemic; and

WHEREAS, generating data which is more representative of the scope of the epidemic can help us better allocate limited resources, target and evaluate prevention efforts, educate the public about the epidemic, and project where the epidemic is going; and

WHEREAS, HIV names reporting may discourage individuals from seeking HIV testing and treatment and the implementation of HIV names reporting is not currently accompanied by guaranteed access to care and treatment; and

WHEREAS, no strong federal privacy law governing health information currently exists and state privacy protections are inadequate; and

WHEREAS, recent court decisions suggest limited or no discrimination protections for asymptomatic HIV positive individuals under the Americans with Disabilities Act (ADA); and

WHEREAS, the negative aspects of name reporting, in the absence of guaranteed access to health care and strong privacy protections, outweigh the potential benefits of this approach; and

WHEREAS, non name-based surveillance systems, such as unique identifier reporting and population based sampling, will support the public health goals of providing data which can help us allocate limited resources, targeting and evaluating prevention efforts, educating the public about the epidemic and projecting where the epidemic is going, while protecting confidentiality and not discouraging people from seeking HIV testing.

BE IT RESOLVED:

That AIDS Action supports the development of non name-based HIV surveillance systems, including unique identifiers, to achieve the public health goals of HIV surveillance.

That AIDS Action opposes name based HIV surveillance.

That AIDS Action calls on the federal government to provide the resources necessary to support the efforts of states to create and improve unique identifier reporting systems and other non name-based surveillance systems without reducing the funding available for prevention programs.

That AIDS Action calls on the federal government to require states which have adopted or may adopt a names reporting system to provide and/or continue a publicly-funded anonymous testing option to ensure that individuals are not deterred from seeking HIV testing.

That AIDS Action calls on the Clinton Administration and the United States Congress to move forward expeditiously to enact and implement a strong federal confidentiality law which serves as a minimum standard for protecting the privacy of all health-related information.

That AIDS Action calls on the federal government to initiate efforts to guarantee access to care and treatment for all HIV positive individuals.

Adopted by the Board of Directors of the AIDS Action Council, October 18, 1997

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

EXECUTIVE SUMMARY OF THE HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION

Changes in the epidemic have led many public health officials to express increasing concern that existing AIDS surveillance efforts are becoming outdated. This has often resulted in the call for some type of HIV reporting system.

The San Francisco AIDS Foundation acknowledges there is a need for improved HIV data, if this information is used appropriately to better plan for future service needs, target and evaluate prevention efforts, and inform resource allocation decisions. **However, we strongly disagree that HIV *names* reporting is necessary to accomplish these goals, and we do not believe that the benefits of names reporting outweigh the potential negative repercussions associated with this type of surveillance system (such as the possibility that some individuals would be deterred from seeking HIV testing and/or treatment under such a system).**

Any system that is developed should meet the goals of HIV surveillance and the criteria by which HIV surveillance systems should be evaluated that are outlined below. Non-names based surveillance systems that may be able to meet these goals and criteria, such as reporting systems that utilize unique identifiers, must be more aggressively examined in an unbiased fashion as a viable alternative to HIV names reporting.

Goals and Appropriate Uses of HIV Surveillance Data

We believe that HIV surveillance should only be designed to help meet the following goals:

- Better determine and understand the demographic and risk profiles of the current epidemic;
- Plan for future health care and social service needs;
- Track new incidence of HIV in order to target prevention efforts;
- Evaluate overall efficacy of prevention efforts;
- Inform rational resource allocation.

Any HIV surveillance system that is developed should include specific mechanisms to ensure that surveillance data is utilized to meet these goals. In addition, although certain activities are worthy goals of HIV testing and treatment programs—such as linking individuals to care and treatment or identifying additional individuals who have possibly been exposed to HIV—these are not appropriate uses of HIV surveillance data. HIV reporting will not make treatment more available or accessible and is not needed to conduct effective partner notification.

Criteria That Should Be Utilized to Evaluate HIV Surveillance Efforts

The Foundation believes there are reasonable and appropriate criteria that must be met to justify the use of any particular HIV surveillance system. Specifically, an HIV surveillance system should:

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

- Not create a disincentive to testing and/or treatment;
- Produce information that is actually utilized for planning and evaluation purposes in a manner that has the potential to improve the community's health;
- Not violate confidentiality and/or civil rights and should include strong enforcement and penalties for disclosure of information;
- Not come at the expense of resources for treatment/services;
- Respect individual choice with respect to name disclosure.

Only by meeting these criteria will a system provide sufficient benefit to outweigh any potential negative or damaging consequences. A mandatory name-based reporting system would run counter to several of these criteria and should under no circumstances be required or encouraged. Other systems that do not rely on names, such as some type of unique identifier system, should be pursued if it is determined that such a system also meets these criteria.

Unique Identifier Reporting Must Be Examined as a Viable Alternative

The primary HIV surveillance system that is considered a potential alternative to names reporting is unique identifier reporting. Under such a system, an HIV-infected individual would not be reported by name to public health officials, but rather by some form of a unique code that could not be traced back to the person. Many have argued that the data regarding the effectiveness of unique identifier systems show that these systems are inadequate and that names reporting is the only viable HIV surveillance system available. The Foundation disagrees with this conclusion. We do not believe that unique identifier reporting systems have been judged fairly in the national debate regarding HIV surveillance systems. Specifically:

- Unique identifier systems have not been funded adequately.
- The evaluation of the current unique identifier systems has not taken into account the fact that these systems are relatively new.
- The standard used to judge unique identifier systems has been set unnecessarily high. Absolutely complete and accurate data is not needed to analyze broad trends in the epidemic.
- The fact that many states have implemented names-based reporting does not provide a legitimate rationale for opposing unique identifier reporting (in fact, approximately 75% of individuals living with HIV reside in states that do not report HIV cases by name).

The Foundation believes that if public health officials commit to providing proper attention and time to developing such a system, a reporting mechanism could be developed that would provide adequate and necessary surveillance data while greatly reducing the public health and privacy concerns related to name based reporting.

In conclusion, the Foundation agrees that improved HIV surveillance data, if used appropriately, could benefit people living with HIV. However, collection of this data must be done in a manner that minimizes the potential for harm to these same individuals. We will continue to work to establish a system that meets both of these important goals.

For a copy of the complete, seven-page position statement, please contact the San Francisco AIDS Foundation Public Policy Department at (415) 487-3080.

HUMAN
RIGHTS
CAMPAIGN

1101 14th Street NW
Washington, DC 20005
website http://www.hrc.org
phone 202 628 4160
fax 202 347 5323

News Release

FOR IMMEDIATE RELEASE
Friday, Oct. 16, 1997

Contact: Kim I. Mills
Phone: (202) 216-1534
Pager: (800) 386-5997

HRC SUPPORTS BETTER DATA ON HIV

Urges Caution as CDC Considers Expanded HIV Surveillance

WASHINGTON -- Recognizing the need for better data on the HIV epidemic in the United States, the Human Rights Campaign called today on the Centers for Disease Control and Prevention to address a number of issues as it proceeds in developing an expanded HIV surveillance system.

"The issue of reporting the names of people with HIV is coming to the forefront, and a number of important concerns must be addressed before such a system is adopted," said Seth Kilbourn, HRC's senior policy advocate for health issues.

Kilbourn outlined the following concerns:

- The need for HIV surveillance data must be fully explained and justified.
- Confidentiality and privacy concerns are legitimate. Any system of expanded HIV surveillance must address these concerns in a real and meaningful way. The use of unique identifiers (as opposed to names) must be fully explored as an option.
- If names are to be used, the CDC must demonstrate that they are an essential part of the surveillance system. Further, the CDC must develop a clearly articulated policy to ensure that the privacy and confidentiality of people with HIV are fully protected.
- Anonymous testing must be accessible to anyone who seeks it. No one should be deterred from getting tested for HIV because of privacy and confidentiality concerns.
- Surveillance systems at the local, state and national level must be separated from any partner notification and contact tracing systems. Surveillance data are a mechanism to obtain accurate information about the state of the HIV epidemic. They must never be used as a registry for any other purpose.

Kilbourn noted that an article in this week's *New England Journal of Medicine* recommends that all states require HIV case reporting to better monitor the AIDS epidemic. The article, written by Lawrence Gostin of the Georgetown University Law Center, John Ward of the CDC and A. Cornelius Baker of the National Association of People with AIDS, states that "unless we revise our surveillance system, health authorities will not have reliable information about the prevalence, incidence and future directions of HIV infection."

Currently, all people who are diagnosed with AIDS are reported by name to state and local health departments. Such reports also include demographic data, risk history and the patient's clinical status. State health departments then delete patient identifying information from the report and send the information to the CDC for compilation into a national picture of the AIDS epidemic. However, as AIDS deaths have declined and people are living longer with asymptomatic HIV disease, a national picture based on the end stages of disease progression may be less useful. The CDC is currently in the process of developing policy and recommendations on expanding its surveillance system to include HIV infection.

The journal article does not explicitly call for reporting the names of people with HIV to state and local health departments. Noting concerns about privacy and discrimination, however, the authors call for more work to ensure community acceptance of HIV case reporting. The article questions the utility of using unique identifiers which do not include the patient's name because they "do not yet provide high-quality, unduplicated HIV data at a reasonable cost."

The American Civil Liberties Union also released a position paper today on HIV surveillance, opposing the use of names reporting to state and local public health authorities. The ACLU asserts that name reporting would discourage people from getting an HIV test, that legal protections are weak, and access to care is not guaranteed for all people with HIV.

"In a perfect world -- in which gay people had full civil rights protections -- names reporting would not be controversial," Kilbourn said. "But as long as people can lose their jobs, their homes or their children merely for being gay, privacy concerns are legitimate."

Ultimately, which diseases to report and how to report them, are state-level decisions. Twenty-six states currently require reporting of HIV by patient name.

"Any effort by the CDC to recommend or require a national system of HIV surveillance must include the principles outlined above, in addition to the acceptance of the affected community," Kilbourn said. "Without that acceptance, any expansion of the HIV surveillance system will surely fail. HRC is committed to meaningful dialogue with the CDC on this issue and hopes that it will adequately address the community's concerns."

The Human Rights Campaign, the largest national lesbian and gay political organization, with members throughout the country, effectively lobbies Congress, provides campaign support, and educates the public to ensure that lesbian and gay Americans can be open, honest, and safe at home, at work, and in the community.

- 30 -

Tracking Today's Epidemic, Not Yesterday's

by
Ronald S. Johnson
Managing Director of Public Policy, Communications, and Community Relations
Gay Men's Health Crisis

Over the past week, since the release of GMHC's statement calling for HIV monitoring in New York State, there has been a great deal of discussion about the issue of reporting names. By recommending the development of a coded unique identifier system, we felt we were clearly expressing our opposition to names reporting. If clarification is needed, however, here it is: GMHC opposes collecting names. A names-based monitoring system, such as the one used for AIDS cases and deaths, is not appropriate for HIV because some people will avoid testing and will miss out on early medical care if the government gets their name.

HIV demands a new system. Monitoring HIV is a necessity and we are in agreement with nearly every one of our sister organizations about that. We at GMHC put ourselves on the line in opening this discussion and we're concerned that the main point of our statement not be lost: we need an anonymous, coded system, and we need it now. If a successful system using unique identifiers has yet to be developed in other states, that doesn't mean one can't be found that works for us here.

New York's current system for tracking the HIV/AIDS epidemic has, over the last eighteen months, given a fragmented picture of an evolving health crisis. Last year New York reported the first drop in AIDS deaths and cases, but could say dangerously little about the record number of people living with HIV and the thousands becoming infected each year. With this incomplete information, our fight is stymied, and all New Yorkers, particularly youth, are endangered.

GMHC has previously opposed plans to report HIV infections, but we are now convinced this step is needed to combat the epidemic today and into the future. As HIV ravages the poor, women and youth, and with new treatments that slow progress to AIDS among many of the newly infected, we must gather data that target prevention and treatment where they are most needed. To accomplish this we need a new monitoring system that assures privacy and answers compelling questions: Who is becoming infected and how? What prevention efforts work and why? What are the characteristics of people being treated on new therapies?

New York's current monitoring system, designed in 1983, tracks the epidemic by counting people who become hospitalized with, or die from, AIDS-related illnesses. The system misses the shift of HIV care from hospitals to outpatient clinics and doctor's offices. It also misses the large numbers of people who have learned they are HIV positive, entered early treatment, and stayed healthy. This progress has rendered obsolete New York's hospital-based system of counting AIDS cases. We have little information to prevent new infections and improve and expand health care for HIV infected people today. Counting only the seriously ill and hospitalized reveals yesterday's epidemic -- infection trends at least ten years old.

The most serious deficiency of the old system is how it ignores our youth and young adults. In the thirty states that already report HIV, young people account for one percent of AIDS cases but twenty percent of newly-acquired infections. Young people are now the engine of the epidemic, but how the fears, foibles, and uncertainties of youth increase their risk remains largely unknown and unexplored. For New York, the implications are clear and chilling.

Many fear monitoring HIV will erode privacy and lead to further discrimination if the government collects personal information on people who are HIV positive. A coded monitoring system must be developed with strong and enforceable privacy protections. The current AIDS monitoring system, in fact, has guarded privacy extremely well for nearly two decades. Public health data in New York State are among the most highly protected form of medical information. As AIDS advocates, we need to focus on the real threat to privacy -- the unregulated free market for our private medical records among insurers, drug companies, industry, and employers.

Our call for a coded monitoring system should not become a vehicle for enacting unrelated, punitive or ineffective HIV policies. Some propose linking a new monitoring system to hiring thousands of new state caseworkers who will track down and notify the sexual partners of all HIV infected people. But counseling about disclosure and protecting sexual partners must be performed by those who already have frequent, trusted contact with infected people. With an estimated 150,000 New Yorkers already infected and infectious, using doctors, nurses, social workers, and community-based organizations for this task is the only practical solution.

Government should not simply monitor the epidemic however. Public health officials and elected leaders must commit themselves to using the data they collect to care for the infected and prevent new infections. The government's record here is cause for concern.

Although the new treatments remain out of reach to thousands, the U.S. Department of Health and Human Services recently announced it was "too expensive" to provide Medicaid to impoverished people with HIV before they become seriously ill. Government-funded prevention efforts also have too often been prudish, ineffective, and inadequately informed by epidemiological data. Until 1992, federal law prohibited targeted prevention for gay men, and federal funding for needle exchange programs remains illegal today. Public health officials and elected leaders must begin to deal frankly with drug use and sexual behavior.

We can wait no longer. HIV is spreading silently and largely undetected, especially among New York's youth. Without a system to monitor newly-acquired infections, we learn only about sensational, tragic cases like those in Chautauqua County. HIV's daily toll on so many young lives remains hidden. A new monitoring system itself will not stem this tide, but it is a crucial first step in forging new strategies for the epidemic's third decade. We must act now, before HIV claims another generation.

Minnesota Department of Health
717 Delaware Street Southeast
P.O. Box 9441
Minneapolis, MN 55440-9441
(612) 623-5000

April 9, 1998

Eric Goosby, M.D.
Director, Office of HIV/AIDS Policy
200 Independence Avenue SW
Room 736-E
Washington, D.C. 20201

Dear Eric:

I appreciate the opportunity that Gus and I had to meet with you, Deborah and Todd in late March. I am writing to share a few thoughts that I had after that meeting. First, the issue of protecting patient confidentiality seems to be an ongoing and almost insurmountable barrier to implementing named HIV reporting in all states. I recognize that this concern is real and will continue to be so despite the best efforts of public health agencies to protect data privacy. Conversely, as a practicing epidemiologist who has worked with disease reporting issues for 15 years, I remain extremely concerned that unique identifier systems will create more problems than they will solve and will not provide the kind of quality data that we need to effectively track the HIV epidemic as part of our overarching prevention strategy.

How can these two perspectives come together? In thinking about this issue after our meeting, it seems to me that the best alternative is to set up systems where providers and laboratories report cases of HIV infection by name (similar to what is done with AIDS case reporting now) with a process that either encrypts the name one way (meaning that it cannot be accessed once entered, but duplicates can be detected) or name digestion after a certain period of time (where the name could no longer be retrieved after a specified time interval). I have heard Mead Morgan from CDC discuss these issues and such systems appear to be feasible at a reasonable cost. It seems to me that this approach would eliminate CSTE's concerns regarding placing added responsibility on providers to generate unique identifiers and keep track of patients in their practices and would also satisfy concerns about inappropriate uses of data since names would not be retrievable after a relatively short period of time. This type of system would also eliminate problems with duplication and would provide a relatively accurate way to track the epidemic at an acceptable cost. The major drawback to such an approach would be that public health officials would not have the opportunity to contact patients directly if new breakthroughs in treatment occur in the future; this would be a trade off in developing such systems.

I would like to hear your thoughts on this approach and whether you think it may offer an alternative to name based or unique identifier systems. In closing, I would like to thank you,

Deborah and Todd for candidly sharing your ongoing concerns with us and I hope that we can work together to move this issue forward on a national level.

Sincerely,

Kristine A. Moore, M.D., M.P.H.
Assistant State Epidemiologist
and Medical Director
Acute Disease Epidemiology Section

KAM:dd

cc: Deborah Von Zinkernagel, Office of HIV/AIDS Policy
Todd Summers, Office of National AIDS Policy
John Ward, M.D., CDC
Gus Birkhead, M.D., CSTE
Willis Forrester, CSTE
John Hybarger, CSTE

1997 CSTE ANNUAL MEETING

CSTE POSITION STATEMENT # ID-19

COMMITTEE: Infectious Disease

TITLE: Increasing Access to Sterile Syringes and Needles to Prevent Transmission of Blood-Borne Infections Associated with Injection Drug Use

ISSUE: For injection drug users (IDUs) who continue to inject, use of sterile syringes and needles is important for prevention of blood-borne infections including HIV. However, the medical and public health value of IDU access to sterile syringes and needles for prevention of blood-borne infection transmission is not widely recognized. Every state has laws or regulations that limit IDU access to sterile syringes and needles.

POSITION TO BE ADOPTED: CSTE recommends that state health departments work with agencies regulating physician and pharmacist practice, professional organizations of physicians and pharmacists, substance abuse treatment providers, and law enforcement agencies to:

- clarify the legitimate medical purpose of use of sterile syringes and needles by IDUs to prevent blood-borne infections;
- repeal prescription requirements for purchase of syringes and needles;
- remove syringes and needles from drug paraphernalia laws;
- remove pharmacy restrictions on sale of syringes and needles; and
- promote the development of community-based programs for safe disposal of used syringes and needles.

BACKGROUND AND JUSTIFICATION:

1) More than one-third of all AIDS cases, and as many as half of new HIV infections are directly or indirectly related to injection drug use.

2) Restrictions on access to sterile syringes and needles for IDUs and criminal penalties for possession of syringes and needles promote multi-person use of syringes and needles and drug injection equipment which allows transmission of HIV and other blood-borne infections.

3) The American Medical Association's *A Physician Guide to HIV Prevention* and the Prevention Services Task Force endorse the one-time use of sterile syringes and needles for HIV prevention among IDUs.

4) After a Connecticut partial repeal of prescription requirement and criminal penalties for syringe and needle possession in 1992, IDUs in that state shifted purchases of syringes and needles to pharmacies, decreased syringe and needle sharing, and most pharmacists reported selling syringes and needles without prescriptions.

COORDINATION WITH OTHER ORGANIZATIONS:

Agency for Response: Association of State and Territorial Health Officials (ASTHO)

Agency for Information: Centers for Disease Control and Prevention (CDC)

CONTACT:

Kristine L. MacDonald, M.D., M.P.H.
Assistant State Epidemiologist
Minnesota Department of Health
717 Delaware Street, S.E.
P.O. Box 9441
Minneapolis, MN 55440-9441
(612) 623-5414 (tel)
krism@mdh-dpc.health.state.mn.us

1997 CSTE ANNUAL MEETING

CSTE POSITION STATEMENT#ID-4

COMMITTEE: Infectious Disease

TITLE: National HIV Surveillance: Addition to the National Public Health Surveillance System

ISSUE: Surveillance for all persons with HIV is needed to address the increasing limitations of AIDS surveillance. HIV surveillance will be unaffected by delays in disease progression and provides information on the leading edge of the epidemic. Estimates of the total number of known persons living with HIV are central for determining medical care and social service needs. In addition, the HIV prevention community planning process has identified additional data needs for effective prevention planning at state and local levels. There is an increasing role for HIV surveillance data to evaluate the impact and outcomes of prevention programs. As treatment extends the lives of HIV-infected persons, effective HIV prevention strategies are crucial to controlling the HIV epidemic. HIV surveillance data are needed to guide and evaluate these efforts.

POSITION TO BE ADOPTED:

CSTE recommends:

1. All states and territories should implement confidential HIV infection reporting by name from health care providers and laboratories based on methods that provide accurate and representative data for all persons confidentially diagnosed with HIV infection.

2. Unique identifiers other than a name not be used for HIV surveillance activities as evaluations of such systems have not shown a level of completeness comparable to name-based systems. In addition, follow-up to determine disease progression and voluntary patient referrals to prevention and treatment services are more difficult in the absence of patient identifiers.

3. States and territories not view confidential HIV infection reporting and continuation of anonymous HIV testing as incompatible. In states and territories where public health officials and community planning groups deem anonymous HIV testing to be an effective adjunct in the response to the epidemic, the continuation of anonymous testing is appropriate. Steps should be taken to assure that persons testing positive in an anonymous setting be referred for medical care and other supportive services.

4. All states and territories encourage the use of HIV surveillance data at the local/state level in the community planning process to identify local needs and resources and to assist the referral of those in need of medical care, prevention or social services.

5. CDC should identify the core data elements needed to monitor newly diagnosed (prevalent) HIV infection, late stage disease (AIDS), and HIV-related deaths. Surveillance methodology should also include the ability to identify recently infected persons, i.e., persons with primary/acute HIV infection, recent seroconverters or high CD4+ cells. (See Attachment 1, Section I)

6. CDC should provide increased funds and technical assistance to ensure the quality and efficiency of HIV surveillance systems and to facilitate the transition from tracking severe HIV disease (AIDS) to monitoring HIV infection (including AIDS).

7. States and territories should continue to ensure the security and confidentiality of AIDS and HIV surveillance data with ongoing technical support from CDC.

BACKGROUND AND JUSTIFICATION:

All U.S. states and territories currently require confidential reporting of AIDS cases to the local or state health department. Since 1981 more than 580,000 cases have been reported in the U.S. AIDS case reporting has formed the cornerstone of our efforts to monitor the HIV epidemic at the national, state, and local levels. HIV prevention efforts are based to a large degree on demographic and HIV risk behavior information collected through AIDS surveillance. Aside from HIV-related mortality data available through vital statistics, AIDS surveillance represents the only nationwide population-based source of data on the HIV epidemic in the U.S.

The use of AIDS surveillance data to monitor the HIV epidemic has important limitations. AIDS represents the most advanced stage of HIV disease which in the absence of effective antiretroviral treatment develops on average more than 10 years after initial HIV infection. Thus, AIDS surveillance is not a sensitive method of detecting emerging epidemic trends and provides an imprecise estimate of the overall burden of the HIV epidemic. Furthermore, recent advances in HIV therapy will increasingly limit the utility of AIDS surveillance data. The recent introduction of protease inhibitors and potent combination antiretroviral therapies has resulted in dramatic clinical improvement among many persons with HIV infection. Preliminary reports suggest that these new treatments greatly slow and may even reverse the progression of HIV disease. Dramatic declines in AIDS-related deaths have already been reported throughout the U.S. and in many regions of the country declines in newly reported AIDS cases are occurring. Early treatment is likely to extend the length and quality of life and may also reduce infectiousness and secondary transmission. AIDS surveillance is inadequate for assessing the impact of these effective and expensive new therapies on the course of the epidemic.

An important concern expressed by community agencies and some public health departments is the possible adverse impact of reporting on the willingness of at-risk persons to seek HIV testing services. Given this potential the continued availability of publically funded anonymous testing should be considered. Also, the recent introduction of commercially available home collection kits for anonymous HIV testing will provide widespread opportunities for anonymous testing in rural as well as urban settings.

HIV surveillance need not necessarily be linked to partner notification activities. Support for voluntary partner notification activities should be developed in the broader context of community planning (or other advisory processes).

Twenty-nine states currently require HIV case surveillance of adults and adolescents and/or children who test positive for HIV antibody and report these data to the Centers for Disease Control and Prevention (CDC). HIV/AIDS case surveillance is conduced by reporting patient and provider names to authorized personnel of state\local health departments. Both Florida and New Mexico have recently passed rules or legislation to initiate HIV surveillance and have targeted implementation dates in late 1997 or early 1998.

In some states that have considered HIV surveillance, community concerns about confidentiality of these data have led to consideration of reporting with non-name identifiers. In two states (Texas and Maryland) HIV surveillance is conducted using numeric codes instead of patient names. Both states have encountered substantial barriers in implementing these systems. Inaccurate and incomplete coding of unique identifiers has led to an inability to accurately link to existing databases limiting the utility of this approach as an effective surveillance method.

In 1989, 1991, 1993, 1995, CSTE adopted resolutions encouraging states to consider implementation of HIV case surveillance.

GOALS FOR SURVEILLANCE:

Local/State/National goals:

a. Obtain a minimum estimate of the number of HIV infected persons

HIV case surveillance is useful because it provides a minimum number of persons known to be HIV-infected in a given area. This will provide for, planning purposes, the best local estimate of the number of persons for whom services may be required. This minimum estimate would provide a more appropriate means for distribution of federal, state and local funds for services.

b. Monitor more recent epidemic infection trends

HIV case surveillance provides data regarding persons who acquired HIV more recently than those reported with AIDS. Among cases reported from 1994 through 1996 in states with HIV reporting, a higher proportion of persons with HIV compared to AIDS were women (29%:19%), African American (56%:46%) and between 13-24 years of age (17%:5%). In addition, an estimated 3,000 to 4,000 persons reported annually in HIV surveillance states have evidence of recent infection, based on CD4 count >700 cells/l, documented seroconversion within 18 months of their HIV diagnosis, or young age (under 24 years). These cases represent over one quarter of recently infected persons in these states. These data may be useful for developing timely targeted prevention interventions to reduce HIV transmission, evaluate HIV counseling and testing programs, and evaluate access to and use of HIV treatment services.

c. Evaluate prevention interventions

HIV surveillance may also be used to target and evaluate specific HIV prevention interventions such as the recommended procedures to reduce the risk of perinatal HIV transmission. For example, a recent CDC analysis found that by September 1995, states with HIV surveillance were able to identify 49% of children who were born to infected mothers in 1993 compared to only 5% of children in states with AIDS reporting alone. These states can most effectively evaluate Public Health Service recommendations for reducing perinatal transmission and counseling and voluntary testing of pregnant women, and monitor changes in rates of perinatal transmission in the most timely way.

d. Epidemiologic profiles for community planning

States conducting HIV surveillance have presented HIV data together with AIDS surveillance data in their epidemiologic profiles for community planning. Community planning groups in areas without HIV reporting have expressed interest in data reflecting more recent transmission patterns. States with HIV surveillance have used male to female ratios in HIV data, which may reflect more current transmission patterns than AIDS data, for calculations of prevalence based on the Survey of Childbearing Women. However, with discontinuation of the Survey of Childbearing Women, HIV surveillance data may become more widely used for estimating prevalence in these states.

e. Referrals to care and services

HIV case surveillance may also be used to provide a basis for offering voluntary referrals to appropriate prevention and treatment programs for HIV-infected persons. In more recent years, some states such as South Carolina, Missouri, Minnesota, and New Jersey are also offering medical and social service referrals for persons reported with HIV infection.

f. Improve efficiency and completeness of reporting

HIV reporting has the added potential benefit of enhancing the efficiency, and thereby reducing the cost, of the current AIDS surveillance program by allowing for a more laboratory-based system of case finding and reporting. A laboratory-based system of reporting of HIV-positive test results and CD4+ T-lymphocyte counts <200 cells/uL would allow fuller and more timely characterization of the epidemic in the U.S.

METHOD FOR SURVEILLANCE:

Surveillance for HIV would be incorporated into existing AIDS surveillance activities by state and local health departments and would be enhanced through laboratory-based case finding and reporting. Reporting by hospital-based infection control practitioners and health care providers would be required.

HIV surveillance should be simple and include a core set of data elements essential for disease monitoring and should be sufficiently similar to AIDS surveillance to provide an integrated flow of information. Data should be available to estimate the number of new HIV diagnoses, HIV and AIDS prevalence and HIV related deaths. Surveillance methods should include laboratory-based case finding and reporting to enhance efficiency and completeness of reporting. Surveillance systems should be flexible enough to keep up with changes in clinical practice and new diagnostic methodologies. The reporting of HIV by hospital-based infection control practitioners, clinicians, health maintenance organizations and other public and private providers of HIV care should be encouraged. HIV surveillance should use the traditional public health practice of including the name with the collected information to assist efforts to eliminate duplicate reports, conduct follow-up epidemiologic investigations and provide voluntary referrals to link clients to services as deemed appropriate.

In addition to core data collection, supplemental surveillance studies should be preformed to address more complex issues such as access to medical care, drug assistance programs, drug resistance, and effectiveness of prevention and treatment interventions. The impact of treatment on risk behaviors and potential infectiousness also need to be determined. These data may be collected through approaches such as representative sampling, sentinel surveillance or projects that target special populations or geographic areas (See Attachment 1, Section 2).

Accordingly, security and confidentiality are of paramount concern for HIV surveillance systems. All programs should periodically review security and confidentiality protections in place and take steps to improve these protections.

CASE DEFINITION:

Human Immunodeficiency Virus (HIV) Infection

Laboratory Criteria for Diagnosis:

Repeatedly positive test for antibody to HIV confirmed by western blot or IFA or specimens that are positive by PCR, viral load testing or viral isolation by culture or other FDA-approved HIV diagnostic or confirmatory tests.

Clinical Criteria for Diagnosis:

1993 CDC Revised AIDS case definition

PERIOD FOR SURVEILLANCE: Permanent

COORDINATION WITH OTHER ORGANIZATIONS:

Agencies for Response: National Alliance of State and Territorial AIDS Directors (NASTAD)
Centers for Disease Control and Prevention (CDC)
Health Research and Services Administration (HRSA)

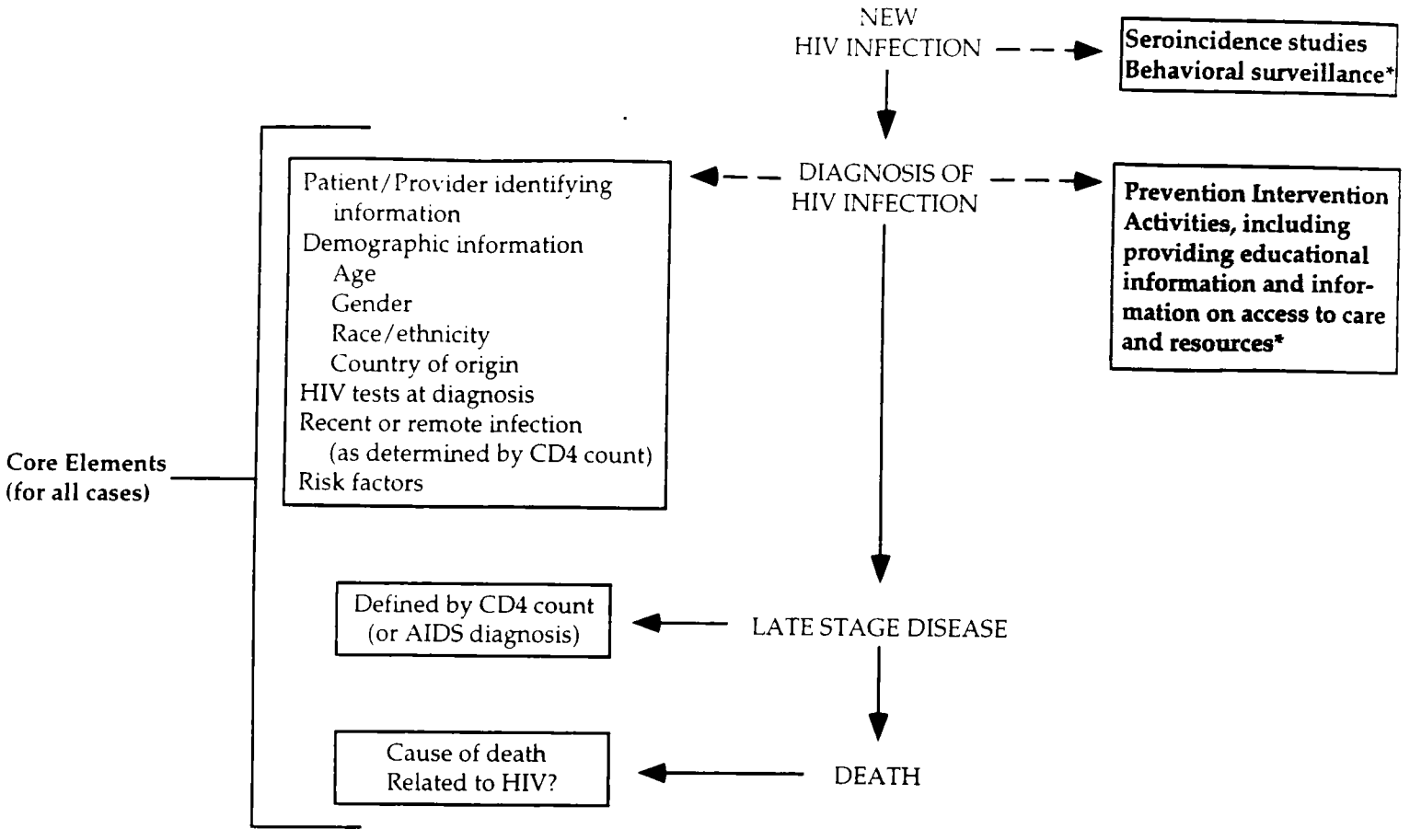
Agency for Information: Association of State and Territorial Health Officials (ASTHO)

CONTACT:

Kristine MacDonald, M.D., M.P.H.
Acute Disease Epidemiology
Minnesota Department of Health
717 Delaware Street, S.E.
Minneapolis, MN 55440
(612) 623-5415 (tel)
krism@mdh-dpc.health.state.mn.us

FRAMEWORK FOR NATIONAL HIV SURVEILLANCE

I. CORE HIV SURVEILLANCE



*Not part of core surveillance, but aspects of an integrated system for monitoring the HIV epidemic and providing prevention services, along with special studies or sampling of issues identified below.

II. SUPPLEMENTAL HIV SURVEILLANCE (RANDOM SAMPLING OR SELECTED POPULATIONS/GEOGRAPHIC AREAS)

Clinical/Treatment Issues:
- Development of opportunistic infections/cancers
- Viral load data
- Treatment response
- Development of resistance to antiviral agents
- Impact on survival

Access Issues:
- Infection prophylaxis
- Treatment access
- Insurance/reimbursement
- Access to other services

Social Issues:
- Impact of treatment on behavior
- Impact of prevention intervention activities
- Other issues

Paul Kawata <pkawata @ nmac.org>
03/27/98 12:46:54 PM

Record Type: Record

To: Paul Kawata <pkawata @ nmac.org>

cc:
Subject: NMAC HIV Surveillance and Names Reporting Position Statement

---

HIV SURVEILLANCE AND NAME
REPORTING POSITION STATEMENT

CDC Proposes a National HIV Surveillance System
Recent advances in the treatment of HIV have led to a delay in progression from HIV infection to AIDS, to declines in opportunistic infections (OIs), and declines in AIDS mortality and AIDS incidence. The number of persons living with HIV infection (prevalence) has increased. AIDS case surveillance has been used to track and monitor the epidemic since the early 1980s. This system is based on reporting diagnosed AIDS cases and therefore does not include the cases of persons living with HIV infection have not progressed to AIDS.

Currently all fifty states and the territories report diagnosed cases of AIDS to the Centers for Disease Control and Prevention (CDC). As of January 1998, thirty one (31) states have implemented name-based HIV surveillance. The advances in HIV treatment, and the changes in the nature of the epidemic, have prompted federal and state public health officials to examine the usefulness of the current national system of AIDS surveillance. CDC officials are now calling for an expansion of the current AIDS surveillance system to include HIV case surveillance. HIV case surveillance can provide public health officials with more reliable information about HIV prevalence and the number of new HIV infections diagnosed each year. HIV case surveillance can also provide information on recent or emerging trends in HIV infections and behaviors that increase risk for HIV transmission. Finally, HIV surveillance can provide information on the impact of the epidemic on specific sub-populations.

On May 21-22, 1997, the CDC and the Council of State and Territorial Epidemiologists (CSTE) convened a consultation in Atlanta, Georgia on the ³Future of HIV/ AIDS Surveillance². The meeting which was designed to discuss the objectives and methods of conducting HIV/ AIDS case surveillance included representatives of national AIDS organizations, community groups and public health officials including , state and territorial, health officials, AIDS directors and epidemiologists. Since then, a national debate has ensued regarding the establishment of a national HIV case surveillance system. One of the major issues of contention in this debate is whether or not HIV surveillance should be conducted using names or unique identifiers (non-name, coded identifiers).

In the January 9, 1998 edition of the Morbidity and Mortality Weekly Report (MMWR), CDC published an evaluation of HIV case surveillance through the use of unique identifiers (UIs) in Maryland and Texas, from 1994 to 1996. CDC highlights many problems with the use of UIs including a high number of

reports with incomplete codes, low rates of completeness in reporting, difficulty in conducting follow-up on specific cases and the absence of behavioral risk data in the system. CDC concluded that the use of unique identifiers limits the performance of an HIV surveillance system and complicates efforts to collect risk behavior information.

Currently CDC is developing a [3]best practices[2] guidance and technical assistance to be provided to state health departments within the next two months regarding the security and quality of HIV/AIDS surveillance. The upcoming guidance will be released within the next 30 days in a special MMWR Recommendations and Reports for public comment. The CDC hopes to publish the final guidance by the summer of 1998.

Throughout the consultations CDC officials have indicated their preference for an HIV surveillance system based on name reporting and have underscored the problems with data generated through the use of unique identifiers. In a meeting in Atlanta on February 16, 1998, CDC officials indicated they would recommend a national system of HIV surveillance based on name reporting in the MMWR Report and Recommendations.

NMAC Opposes HIV Name Reporting

The National Minority AIDS Council (NMAC), recognizes the critical need to develop a national HIV surveillance system to improve the monitoring of recent trends and patterns in the HIV epidemic, provide essential data to plan, target and evaluate HIV prevention services and to guide decision-making regarding the allocation of funding. However, NMAC does not believe that HIV name reporting is necessary to accomplish these goals and may in fact result in adverse public health consequences.

NMAC is firmly opposed to HIV name reporting because it poses significant social risks, particularly for people of color-- including women , immigrants, gay men and substance abusers. Name reporting may serve to hinder rather than promote important public health goals by deterring individuals from seeking HIV testing in the first place, and for those who test positive, delaying early entry into treatment.

Background

As a result of breakthroughs in scientific knowledge of viral load and advances in HIV clinical care with triple combination therapy (including protease inhibitors), the National Institutes of Health (NIH) issued clinical guidelines' emphasizing early and aggressive treatment of HIV infection. These developments highlight the importance of early HIV testing, so that individuals can learn their sero-status, and if HIV positive, benefit from the new drug therapies by entering treatment as early as possible.

In 1997, for the first time in the history of the epidemic, CDC reported a decline in annual AIDS deaths (23% from 1995-1996), and in the number of new AIDS cases (6% from 1995-1996). CDC attributed the declines in AIDS mortality and incidence to the advances in HIV clinical care with triple combination therapies and the progress made in treating opportunistic infections (OIs). The number of people living with AIDS (AIDS prevalence) also increased by 11% between 1995 and 1996.

There are over 235,000 persons living with AIDS in the United States and the CDC estimates that there are between 650,000 and 900,000 persons living with HIV in this country. The nature of the HIV epidemic is dynamic and evolving. There have been significant increases in HIV infections among women, people of color, including gay men, injection drug users and youth. There have also been significant increases in the number of persons infected

through heterosexual contact. Regionally the epidemic is evolving and has expanded significantly in the South, as well as, in rural areas.

AIDS surveillance has been the primary vehicle to monitor the epidemic in the United States. However, with the increase in the number of people living with HIV, AIDS case reporting alone is becoming less representative of recent trends and is therefore less useful in monitoring and tracking the front end of the epidemic. CDC, is therefore recommending the implementation of a national HIV surveillance system and will more than likely recommend that such a system be based on name reporting.

AIDS Surveillance in the United States

The CDC is responsible for a national AIDS surveillance system which requires the reporting of diagnosed AIDS cases by name to local and state health officials. Since 1981 all states, the District of Columbia, Puerto Rico, and other territories have conducted name based AIDS case reporting. Identifying information is removed at the local level and health officials provide the CDC with coded AIDS case reports.

The CDC uses this data to develop a national profile of the AIDS epidemic. The data is also used to conduct comprehensive epidemiological studies and develop reports on AIDS trends based on different demographic indicators such as race/ethnicity, gender, age, area of residence and mode of exposure.

The current national AIDS case surveillance system gives us a picture of the late stages of the epidemic, but it can not provide us with an accurate snapshot of where the front end of the epidemic is today. People living with HIV who do not yet meet the CDC criteria for an AIDS diagnosis are not counted in this surveillance system.

HIV Surveillance in the United States

As of January 31, 1998, thirty one (31) states have implemented name based HIV surveillance as an extension of their existing name based AIDS surveillance systems. Twenty eight (28) states have confidential, name-based HIV infection reporting for adults. These include: Alabama, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming. Three states, Connecticut, Texas, and Oregon have confidential name-based reporting HIV infection reporting for pediatric cases only. Two states- Texas and Maryland - use non- name based (unique identifier) HIV case surveillance for non-pediatric cases.

Of the ten (10) states with the highest rates of AIDS, only New Jersey, Florida and Louisiana have name based HIV surveillance. New York and California, which together account for 35% of the cumulative AIDS cases reported in the country, do not have HIV name based case reporting. Massachusetts has recently decided to implement a non-named HIV reporting system. Other high incidence states/territories like Pennsylvania, and Puerto Rico do not have HIV case reporting.

Availability of Anonymous HIV Testing

The availability of accessible anonymous HIV testing options, for persons who want to know their sero-status but do not want to disclose their names, is a critical component of any HIV surveillance system. Data recently released from a CDC sponsored study (the Multi-State Evaluation of Anonymous HIV Testing and Access to Medical Care), indicate that anonymous HIV testing contributes to enhancing early access to HIV testing and medical care.

Persons testing in anonymous testing sites presented for testing and medical care earlier in their HIV disease course than did confidential testers. Furthermore anonymous testers, experienced an average of 387 more days in HIV related medical care prior to an AIDS diagnosis than confidential testers.

According to the CDC, as of May 1997, forty (40) states, the District of Columbia and Puerto Rico provided anonymous HIV testing options. Twenty one (21)) out of the thirty one (31) states reporting cases of HIV by name provide anonymous HIV testing as an option. Ten (10) states which have HIV name reporting do not provide anonymous testing as an option. These include: Alabama, Idaho, Mississippi, Nevada, North Carolina, North Dakota, South Carolina, South Dakota, Tennessee and Wyoming.

As the CDC moves to implement a national system of HIV surveillance, it must ensure that accessible anonymous HIV testing options are available in every state, the District of Columbia. Puerto Rico and the territories.

People of Color and HIV/AIDS

Racial and ethnic minority populations have been disproportionately affected by HIV and AIDS since the early days of the epidemic in the United States. Through June 1997, the CDC had received reports of 612,078 cases of AIDS among persons in the United States, including 216,980 cases among African Americans, 109,252 among Hispanics, 4,370 among Asians/Pacific Islanders, and 1,677 among American Indians/Alaskan Natives. Through June 1997, 54% of reported AIDS cases were among people of color. African Americans and Hispanics together make up 53% of the cases although these two population groups represent an estimated 13% and 10%, respectively, of the total U.S. population.

People of color make up the majority of people with AIDS in the United States, yet these populations are not benefiting from the advances in HIV therapies at the same rates as their white counterparts. While AIDS deaths declined among men and women; among all ethnic/racial groups; and in all risk/exposure categories, the declines were highest among Whites (-32%) as compared to African Americans (-13%) and Hispanics (-20%). Furthermore, males (-25%) experienced a greater decline in AIDS related mortality than did females (-10%), and men having sex with men (MSMs -30%) experienced greater declines than did male injection drug users (IDUs -17%), MSM/IDU (-25%) or heterosexual males (-8%).

The largest proportionate decreases in AIDS related opportunistic infections (OIs) occurred among non
Hispanic White MSMs (-15%), and non-Hispanic White (-17%) and African American (-13%) MSMs/IDUs. AIDS-OI incidence leveled among non-Hispanic blacks (0%). AIDS OIs increased among women (2%). The largest proportionate increases in AIDS OIs incidence occurred among heterosexual non-Hispanic African American men (19%), heterosexual Hispanic men (13%), heterosexual non-Hispanic African American women (12) and Hispanic heterosexual women (15%).

Despite the promise of the new drug therapies, significant disparities persist in AIDS morbidity and mortality by gender, race/ethnicity, and mode of exposure to HIV infection. Any national surveillance system must collect data on these populations in order to assess the patterns and trends in the epidemic and the long term impact of HIV prevention and HIV care services on these groups.

HIV Testing in the United States

About a third (32%) of American adults have been tested for HIV. The

majority are tested in HMOs or physicians offices (28%), hospitals (33%) and emergency rooms (4%). About one fifth (22%) are tested in publicly funded HIV testing sites: HIV counseling and testing sites (13%), STD clinics (6%), Correctional facilities (2%), and drug treatment clinics (1%). There is also a national network of alternative test sites where anonymous HIV testing is available.

The number of HIV tests conducted in publicly funded sites have increased from 79,000 in 1985 to more than two million in 1994. Close to fifty five (55%) percent of the tests performed were among women and forty five percent (45%) among men. About half of the tests performed were among White persons (48.9%), while African American (32.4%), Hispanic (14.6%), Asian Pacific Islander (1.6%), and Native Americans (0.6%) together accounted for 49% of the remainder of the tests performed. Of the total tests performed, 42,562 were HIV positive. More than two third of all HIV positive tests were among people of color-African American (47.5%), Hispanic (20.5%), Asian Pacific Islander (0.6%), and Native Americans (0.4%). Close to three quarters of the HIV positive tests were among men (72%) and twenty eight percent were among women (28%).

While heterosexual injection drug users (IDUs) accounted for 5.7% of the tests performed they accounted for 17.5 % of the HIV positive tests. Persons with a reported exposure related to male to male sex (MSM) accounted for 6.7% of the tests performed but 29.3% of the HIV positive tests. MSM/IDUs accounted for 0.5% of the HIV tests but 3.9% of the HIV positive tests. Together persons with a reported history of IDU or MSM accounted for over 50% of the positive tests in 1994. Persons reporting heterosexual exposure as their risk of HIV infection accounted for 37.8% of all those tested but 28.4% of those testing positive.

About one third (30%) of adults who are tested do so only to find out whether they are infected. Other reasons cited for taking an HIV test include: hospitalization or surgery (12%); application for insurance (16%); military induction (7%); referral by doctor, health department or sexual partner (7%); or for immigration-related reasons (4%).

HIV/AIDS Stigma and Discrimination

There are many reasons why people may avoid HIV testing or learning their test results. These included denial of potential risk for HIV infection, lack of a regular source of health care, lack of knowledge of testing resources, and concerns regarding undesired disclosure of the test results. Many people who test positive for HIV, fear disclosure of their status to governmental authorities including the Immigration and Naturalization Service (INS), and the child welfare system. They may also fear disclosure of their status within their own communities because of the risk of stigmatization.

The potential for discrimination continues to be a real threat, and may deter individuals from seeking HIV testing. Reports of HIV-related discrimination include denial of insurance, housing, employment, and other private or public benefits. The federal government continues to deny HIV-positive individuals entry into the Peace Corps, the State Department, the Job Corps or the US military. HIV positive immigrants may also be denied entry into the country or permanent resident status.

Fears of social risks such as stigma and discrimination may deter some persons from seeking out HIV testing in the first place, and some individuals who are tested for HIV antibodies from returning for their results. A national survey of more than 13,000 adults explored whether those at highest risk were using public programs for HIV counseling and

testing (the National AIDS Behavioral Survey). A high proportion -more than 60% of those at highest risk- had not yet been tested for HIV antibodies. Approximately 37% of those who tested at publicly funded clinics in 1990 did not return for their results.

Social stigma associated with HIV/AIDS persists in many affected communities and permeates our society as a whole. The CDC's early use of the term 'risk groups' to identify populations most affected by AIDS laid the groundwork for AIDS stigma. These so called 'risk groups' which included gay men, sex workers, Haitian immigrants, intravenous drug users, African Americans, Latinos and primarily women of color, were already marginalized populations within American society.

The association of marginalized groups with HIV/AIDS led to fears and negative societal attitudes towards the epidemic and made it easy for people who did not identify as members of the 'risk groups' to blame the populations most affected for the epidemic. The discriminatory treatment suffered by the Haitian community in the early days of the epidemic when CDC defined Haitians as a risk group, for example, laid the groundwork for the now widespread race-related HIV/AIDS stigma.

Because the sexual and drug use risk behaviors associated with HIV transmission were viewed as entirely voluntary, as well as, offensive and immoral by the larger society, persons with HIV/AIDS were perceived to have gotten what they deserved. Members of communities of color became doubly and triply stigmatized by virtue of their racial/ethnic identities, immigrant status and association with HIV/AIDS risk behaviors and groups. This stigmatization fostered intensified feelings of guilt, shame, responsibility and rejection within the affected communities and led many people to live with HIV/AIDS in secrecy.

HIV name reporting will produce different social risks for different populations. Despite laws prohibiting AIDS discrimination, people with HIV and AIDS continue to experience discrimination. Some proponents of HIV name reporting, minimize fears of discrimination by highlighting the strong legal confidentiality and anti- discrimination protections now in place. Unfortunately, these protections are now being challenged in the courts. Anti- discrimination protections for HIV+ persons will be undermined if the Supreme Court upholds the recent rulings of lower courts indicating that the provisions of the Americans with Disabilities Act (ADA) do not apply to HIV+ asymptomatic persons.

While legal protections may offer some groups affected by HIV recourse and reassurance in the face of discrimination, these protections are of most value for persons who have jobs, private health insurance, and housing, as well as those who receive medical care and seek other professional services. In addition, legal recourse is time consuming and can be expensive. Many low income people living with HIV/AIDS have neither the time nor financial resources to see a discrimination complaint or case run its course in the legal system.

Moreover, the legal system itself often poses a social risk for poor people and ethnic/racial minorities. Their fears and mistrust of government are generally rooted in their previous experiences with the legal and criminal justice systems. They also understand that protections which exist today, may be changed and replaced by punitive and coercive policies or laws in the future.

America is seeing a resurgence of racism and nativism as evidenced by the recent legislation passed on immigration 'reform', welfare 'reform' and

SSI/SSDI eligibility. One of the adverse outcomes of these policy changes was the loss of Medicaid coverage for many low income and disabled individuals. This plethora of negative policies and legislative initiatives which specifically targeted and threatened the well being of legal and undocumented immigrants, single mothers and substance abusers are good examples of what is possible within the current political climate. These very groups may also end up being the prime targets of the misguided efforts underway to criminalize HIV transmission.

Other social risks related to disclosure of HIV positive status may include: withdrawal of emotional and or financial support from a partner, emotional and /or physical abuse, rejection by family members, significant others and/or the communities a whole or the loss of children to the child welfare system.

The HIV surveillance system will only be as good as the data it collects. By its very nature HIV case surveillance will only collect data on those persons who get tested. If large numbers of highly affected populations do not seek testing or avoid it because of real or perceived social risk, then the system will not be representative of the front end of the epidemic. If we want to reduce the perception of social risk we need to address the factors that produce the perceptions among different populations. While there is value in HIV surveillance, the question becomes whether we need case surveillance by name based reporting to track the epidemic or whether we can use other mechanisms such as sero-surveys and sentinel studies to estimate HIV trends in different populations and regions.

HIV Testing and Access to Care

Proponents of HIV surveillance have argued that in the new era of HIV, with available drug therapies, individuals should know their HIV status in order to access care and treatment. While we agree this is an important goal, the tragic fact is that not all people have access to care or the new drug therapies. These groups include the homeless, incarcerated persons, poor women who are not pregnant, people of color, people living in rural areas, immigrants and high numbers of working poor who do not qualify for public medical assistance nor are covered by their employers.

Recent studies have shown that the new drug therapies are not being prescribed for all those who need them. Even states with expansive HIV care programs such as New York are not reaching all those who need the drugs uniformly. People of color and women are not experiencing the same access to these promising therapies as their White and male counterparts. New York City, accounts for 16% of the total AIDS cases in the country. In this epicenter people of color make up over 70% of the reported AIDS cases (African Americans- 40%, Hispanics 31%) and women make up 21% of all cases.

However, a study conducted by Columbia University School of Public Health in New York City, found that of 700 patients, 33% of the White patients reported using combination therapies that include protease inhibitors compared to 12% of African American and 19% of Hispanic patients. Another important finding was that the most advanced medications were more likely to be prescribed when the patient was getting health care in a private physician's office rather than a hospital or community clinic. Men who contracted HIV through homosexual sex were twice as likely to be treated with a combination of drugs and protease inhibitors than are other populations with HIV including substance abusers. African American patients were less likely than White or Hispanic patients to take combination therapies. Over fifty percent (54%) of the African Americans in the study were not taking antiretroviral drugs as compared to 35% of the White, and

38% of the Hispanic patients in the study. (NY Times, Sunday July 27, 1997).

Furthermore, the benefits of early intervention are not available to many people who find out about their HIV status late in the course of disease progression. A study conducted by Wortley, et. al., in 1995 found that 36% of the people who are diagnosed with AIDS, were first tested for HIV within two months of their AIDS diagnosis and 51% within a year of their infection.

It is critically important to examine the social context of the populations that are testing late in their HIV disease course and to identify barriers to testing. It is important to understand the factors that deter people from testing or seeking care in order to develop more effective strategies to promote HIV testing and improve access to care for those who test positive.

NMAC Recommendations

NMAC recognizes the need for a national system of HIV surveillance and supports CDC's efforts to provide states/territories with guidance to develop and implement HIV surveillance systems. However, NMAC opposes HIV name reporting, and is very concerned that CDC will essentially force states to implement named-based HIV surveillance systems by making federal funding contingent on a state's ability to meet strict data quality standards for reporting HIV cases to the CDC. NMAC believes that a national system of HIV surveillance is important, and must be as comprehensive as possible to effectively monitor trends in the HIV epidemic. Such a system must be capable of getting an accurate profile of the demographic distribution of the epidemic by race/ethnicity, gender, age, region, and by mode of exposure/transmission. Reliance on HIV case reporting alone will not provide us with complete data on the nature and extent of the HIV epidemic. A comprehensive HIV surveillance system must therefore include HIV case surveillance, as well as, other types of surveillance activities such as population based sero-surveys, sentinel studies, incidence and prevalence studies and behavioral surveillance.

NMAC strongly recommends that the CDC consider and address the following elements in its up coming guidance to states on the development and implementation of HIV surveillance systems:

* The guidance for the implementation of HIV surveillance for states and territories provided by the CDC, should not explicitly promote the use of name-based reporting system.

* CDC guidelines must support local autonomy and offer states/territories support and flexibility to conduct HIV surveillance through name or non-name based systems. States/territories must be able to select the type of HIV surveillance system which is best suited to meet public health goals and respond to the needs of the communities in their jurisdictions

* CDC must provide federal funding to states/territories for the development, implementation and evaluation of an HIV surveillance system, irrespective of the type of system they select.

* CDC should make federal funds available to jurisdictions to undertake demonstration projects that explore non-name based reporting models that can be made available to states/territories. These systems should ensure that the case reporting identifiers are not linked to names nor any other existing identification system such as Social Security numbers or driver's licenses.

* The CDC must ensure that HIV testing programs and surveillance systems guarantee maximum confidentiality protections and encourage those at highest risk to be tested. HIV testing systems that deter, even a small number of individuals at high risk of HIV infection from testing should not be adopted nor supported by federal funds

* CDC must develop stringent security requirements for state maintenance of personally identifiable surveillance information, including requiring time limitations on maintaining lists of names of individuals living with HIV and/or AIDS as a condition of receipt of federal surveillance funds.

* CDC must develop a core set of model state confidentiality and privacy laws with which states must comply as a condition of receipt of federal surveillance funds. These laws must also prohibit the disclosure of HIV positive test reports to any governmental agencies or private entities for the purpose of denial of benefits, child welfare or criminal proceedings or law enforcement. Model legislation should include stringent civil and criminal penalties for such disclosures.

* CDC must develop and fund campaigns that are culturally competent and linguistically appropriate to aggressively promote HIV testing and reduce barriers to testing. Tailored campaigns that reach populations at highest risk of HIV infection, including people of color, youth, women, substance abusers and gay men should be given top priority.

* HIV testing should be voluntary and pre and post test counseling should be available and provided to diverse ethnic/racial and demographic groups within the context of their culture and in their primary language.

* The CDC must require that states offer accessible anonymous HIV testing options as a condition of receipt of federal surveillance funds to minimize the impact that HIV reporting will have on deterring individuals from seeking testing.

* HIV surveillance must not be linked to partner notification.

* Federal agencies must recognize that all AIDS and HIV surveillance systems are incomplete and must therefore use corrective factors for federal funding formulas to ensure equitable distribution of resources.

* CDC must ensure that HIV surveillance data include the self reported race/ethnicity and national origin/primary language of the person in accordance with the United States Census categories.

* HIV case surveillance must be supplemented with population specific seroprevalence surveys and sentinel studies. These population based studies must include people of color, youth, and women. Studies should also include underreported and underserved populations including, Asian and Pacific Islanders, Native Americans/Alaskan Natives, the homeless, and incarcerated populations.

* Surrogate data on population trends and co-morbidity factors such as STDs, teen pregnancy, substance abuse and tuberculosis should be used to supplement HIV surveillance data for the purpose of HIV community planning.

Name debate complicates HIV tests

To name or not to name: that is the question. But is it the *right* question?

The Texas Health Department has recommended that physicians and HIV testing labs be required to report the names of all Texans infected with HIV, the virus that causes AIDS. Much debate has been focused on "names vs. no names" reporting. But regardless of one's position on names reporting, it is clear that definitive data on the incidence of HIV infection is essential if we are to end this epidemic. Our focus, therefore, should be on how best to collect such data in the least intrusive manner consistent with protecting the public health.

THOMAS HENDERSON

Tracking only AIDS cases, as now is done, tells us less and less about how HIV infection is spreading today. Because it may take a decade or longer for HIV disease to progress to AIDS, the resulting snapshot is of infection patterns years ago rather than of what is happening now.

When AIDS emerged in the early 1980s, the surveillance of AIDS cases, including reporting the names of people with AIDS to public health authorities, began almost immediately and with little controversy. Names reporting was a generally accepted public health response that had been used for certain other diseases. Also, individuals then diagnosed with AIDS already were in the late stages of HIV disease. Those people usually died quickly, and in the interim, their struggle for survival overwhelmed any attempt to lead a "normal life."

Today, new medical treatments can prolong the lives of many people with HIV and significantly delay the time from infection to AIDS. People who learn their HIV-positive status soon after infection and who have the resources to begin appropriate combination drug therapies can expect to live productive lives for many years. But that outcome is contingent on their continuing ability to receive appropriate medical care. That often means keeping their jobs and insurance. Privacy concerns, therefore, are more important than ever.

The Americans with Disabilities Act was hailed as a hallmark in the protection from discrimination of individuals living with HIV/AIDS. But recent court decisions have cast serious doubt on its application to those with asymptomatic HIV. Public health authorities argue that they routinely handle sensitive information in a confidential manner, and, in fact, their record has been quite good. But once public health officials have compiled a list of HIV-positive individuals, there is no way to safeguard such a list from future overzealous "public health" efforts or misguided political mischief.

Although there are many ways of conducting HIV surveillance while maintaining the anonymity of people with HIV, the Texas Health Department supports names reporting as a cheap and easy surveillance system that should be used for HIV infection. But what are the real costs?

Many studies have shown increased resistance to HIV testing by African-Americans, Latinos, gay and bisexual men, immigrants and other populations that historically have suffered discrimination, if they are told their names will be reported to government officials. As the epidemic shifts further into communities of color, mistrust resulting from the infamous Tuskegee syphilis study and this country's history of discrimination under the guise of public health concerns shouldn't be underestimated.

Rather than helping to control the spread of HIV/AIDS or encouraging early medical intervention, names reporting is likely to lead to decreased testing and care for those most at risk.

In expressing its "strong reservations regarding the use of a national HIV names reporting surveillance system," the President's Advisory Council on HIV/AIDS recently urged the Centers for Disease Control to "issue a comprehensive public report on ... the impact of different surveillance systems on seeking ... HIV testing and care ... and (of the) potential discriminatory impacts on individuals and communities at risk for HIV infection." The Texas Health Department should do no less. The risk/benefit ratio for HIV names reporting is simply too great.

Thomas Henderson of Austin is a person living with AIDS and a member of President Clinton's Advisory Council on HIV/AIDS.

VIEWPOINTS

Viewpoints Editor Bob Moos

Viewpoints is a daily forum for a diversity of opinions and does not necessarily reflect the editorial positions of The Dallas Morning News. We welcome submissions. Please address columns to: Viewpoints, The Dallas Morning News, Box 655237, Dallas, Texas 75265. Or send them by facsimile to (metro 972) 263-7456.

The New England Journal of Medicine -- February 26, 1998 -- Volume 338, Number 9

CORRESPONDENCE

National HIV Case Reporting

To the Editor:

Although it is true that Maryland's surveillance system for human immunodeficiency virus (HIV), which has been in effect since 1994, is still being refined and improved, we have found that it has allowed us to perform all the public health functions described in the article by Gostin et al. (Oct. 16 issue). (1) Maryland's system of HIV surveillance by means of unique identifiers has allowed linkage of HIV case reports to death records, has assisted in investigations of unusual strains of HIV, (2) and has been used to inform decisions about allocating funds for service delivery. Our experience suggests that important epidemiologic information can be obtained through a non-name-based surveillance system.

Given the traditional American concern about the privacy of medical records and the very real potential for discrimination against people infected with HIV, we believe that our system provides the benefits of epidemiologic monitoring of the epidemic and averts the creation of barriers to HIV testing and treatment among those concerned about confidentiality. We suggest that states considering HIV surveillance investigate non-name-based HIV-surveillance systems as an important option.

Liza Solomon, Dr.P.H.
Georges Benjamin, M.D.
Maryland Department of Health and Mental Hygiene
Baltimore, MD 21202

References

1. Gostin LO, Ward JW, Baker AC. National HIV case reporting for the United States --a defining moment in the history of the epidemic. N Engl J Med 1997;337:1162-7.
Return to: Text

2. Sullivan PS, Do AN, Robbins K, et al. Surveillance for variant strains of HIV: subtype G and group O HIV-1. JAMA 1997;278:292.
Return to: Text

To the Editor:

The information already available has not been used to prevent HIV transmission among injection- drug users, and widespread HIV case reporting, however meritorious, will not improve that situation.

AIDS-surveillance reports present sufficiently clear and reliable information on the prevalence, incidence, and direction of the epidemic. They indicate a shift in primary risk behavior to injection-drug users, in whom approximately 50 percent of new infections are estimated to occur. (1) The disproportionate impact of the twin epidemics of drug use and AIDS on minority groups, particularly minority women, and among neonates is well documented. (2) On the basis of evidence that HIV is transmitted among injection-drug users through shared use of contaminated needles -- which, particularly in the United States, is necessitated by legal restrictions on drug paraphernalia -- European countries have liberalized paraphernalia policies as a specific HIV-prevention strategy for this group. However, driven by a war-on-drugs ideology rather than by public health and epidemiologic imperatives, the United States has not taken this simple step and thus has unleashed the epidemic among injection-drug users. (3)

This burgeoning pool of infected injection-drug users is concentrated in poor, urban, and predominantly minority neighborhoods, where the epidemic continues to worsen. Relatively small declines in the numbers of deaths from AIDS among members of minority groups (decreases of 2 percent among non-Hispanic blacks and 10 percent among Hispanics as compared with 21 percent among non-Hispanic whites) are a sad commentary on those left behind (4) despite general "advances." Unless rational policy changes allowing drug users to buy and carry their own injection equipment are enacted, HIV case reporting will have no effect on this population.

M. Daniel Fernando, Ph.D.
550 E. 16th St.
Brooklyn, NY 11226

References

1. Holmberg SD. The estimated prevalence and incidence of HIV in 96 large US metropolitan areas. Am J Public Health 1996;86:642-54.
Return to: Text

2. Gostin LO, Lazzarini Z, Jones TS, Flaherty K. Prevention of HIV/AIDS and other blood-borne diseases among injection drug users: a national survey on the regulation of syringes and needles. JAMA 1997;277:53-62.
Return to: Text

3. Fernando MD. AIDS and intravenous drug use: the influence of morality, politics, social science, and race in the making of a tragedy. Westport, Conn.: Praeger, 1993.
Return to: Text

4. Update: trends in AIDS incidence --United States, 1996. MMWR Morb Mortal Wkly Rep 1997;46:861-7.
Return to: Text

To the Editor:

In June of 1988, the Presidential Commission on the Human Immunodeficiency Virus Epidemic, established by President Ronald Reagan, issued its final report. Its first point states:

states:

> The term "AIDS" is obsolete. "HIV infection" more correctly defines the problem. The medical, public health, political, and community leadership must focus on the full course of HIV infection rather than concentrating on later stages of the disease. Continual focus on AIDS rather than the entire spectrum of HIV disease has left our nation unable to deal adequately with the epidemic. Federal and state data collection efforts must now be focused on early HIV reports, while still collecting data on symptomatic disease. (1)

Unfortunately, this sound recommendation was not acted on.

It is encouraging that many in the activist community and in academia are now supporting sound HIV policies. However, we should remember it was these same activists and academics who helped establish a very flawed policy in the first place. To continue to go to them for direction seems ill advised in the light of the admissions they now make regarding the sound HIV policy they fought against for so long.

Tom A. Coburn, M.D.
U.S. House of Representatives
Washington, DC 20515-3602

Shepherd Smith
Americans for a Sound AIDS/HIV Policy
Washington, DC 20041

References

1. Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, June 24, 1988. Washington, D.C.: Government Printing Office, 1988:87-9. (GPO publication no. 0-214-701:QL3.)
Return to: Text

The authors reply:

To the Editor:

The three letters in response to our article are representative of a growing consensus that a national system of HIV surveillance is essential for effective monitoring of and public health response to the HIV/AIDS epidemic. Our proposal for national HIV reporting will, of course, not solve all the perplexing public health and human-rights problems presented by the epidemic. HIV reporting is likely to demonstrate an increasingly disproportionate burden of infection among injection-drug users. In previously published research, we have strongly supported greater access to sterile injection equipment, as aptly suggested by Dr. Fernando. (1)

Drs. Solomon and Benjamin raise perhaps the most important intellectual challenge to a national system of named HIV reporting. Given the understandable concern about privacy, names should not be collected by the government unless it is necessary to achieve important public health purposes. Unfortunately, the data from Maryland do not demonstrate that a system of unique identifiers can provide accurate and reliable data. A recent evaluation of

system of unique identifiers can provide accurate and reliable data. A recent evaluation of the Maryland system supported by the Centers for Disease Control and Prevention found substantial limitations. (2) Of 9971 laboratory reports entered in the Maryland system from July 1994 through December 1996, 29 percent of the reports were missing a portion of the unique identifier, including 22 percent that were missing the social security number (the most specific component of the unique identifier). The Maryland system is also limited by a low rate of completeness of reporting (50 percent), an inordinate number of duplicate reports, and a lack of HIV-risk information. Finally, a unique-identifier system may create additional risks to privacy by increasing the number of surveillance registries. In order to collect follow-up epidemiologic information, private physicians have to maintain logs that link the unique identifier to a name-based medical record. These multiple registries in the private sector may defeat the privacy purposes behind unique-identifier systems.

Congressman Coburn and Mr. Smith support named HIV reporting but suggest that public health officials, community-based organizations, and scholars have lost any legitimate claim to leadership. This is an unfortunate implication coming from two leaders in American politics. Our positions on HIV policies are not formed by political or ideological beliefs. Rather, they are based on objective assessments of the science and of the public health, which necessarily must take account of the medical benefits to and the human rights of people with HIV infection or AIDS. It is not we who have changed, but the epidemic. Given the remarkable progress in medical treatment and a more humane social and legal response to AIDS, new ways of thinking about the epidemic become critically important. We need to create a national HIV-surveillance system that is scientifically sound and supported by the public it serves.

Lawrence O. Gostin, J.D.
Georgetown/Johns Hopkins Program on Law and Public Health
Washington, DC 20001

John W. Ward, M.D.
Centers for Disease Control and Prevention
Atlanta, GA 30333

A. Cornelius Baker
National Association of People with AIDS
Washington, DC 20005

References

1. Gostin LO, Lazzarini L. Prevention of HIV/AIDS among injection drug users: the theory and science of public health and criminal justice approaches to disease prevention. Emory Law J 1997;46:587-696.
Return to: Text

2. Evaluation of HIV case surveillance through the use of non-name unique identifiers --Maryland and Texas, 1994-1996. MMWR Morb Mortal Wkly Rep (in press).
Return to: Text

Please send me the article.

The New England Journal of Medicine -- February 26, 1998 -- Volume 338, Number 9

CORRESPONDENCE

National HIV Case Reporting

To the Editor:

Although it is true that Maryland's surveillance system for human immunodeficiency virus (HIV), which has been in effect since 1994, is still being refined and improved, we have found that it has allowed us to perform all the public health functions described in the article by Gostin et al. (Oct. 16 issue). (1) Maryland's system of HIV surveillance by means of unique identifiers has allowed linkage of HIV case reports to death records, has assisted in investigations of unusual strains of HIV, (2) and has been used to inform decisions about allocating funds for service delivery. Our experience suggests that important epidemiologic information can be obtained through a non-name-based surveillance system.

Given the traditional American concern about the privacy of medical records and the very real potential for discrimination against people infected with HIV, we believe that our system provides the benefits of epidemiologic monitoring of the epidemic and averts the creation of barriers to HIV testing and treatment among those concerned about confidentiality. We suggest that states considering HIV surveillance investigate non-name-based HIV-surveillance systems as an important option.

Liza Solomon, Dr.P.H.
Georges Benjamin, M.D.
Maryland Department of Health and Mental Hygiene
Baltimore, MD 21202

References

1. Gostin LO, Ward JW, Baker AC. National HIV case reporting for the United States --a defining moment in the history of the epidemic. N Engl J Med 1997;337:1162-7.
Return to: Text

2. Sullivan PS, Do AN, Robbins K, et al. Surveillance for variant strains of HIV: subtype G and group O HIV-1. JAMA 1997;278:292.
Return to: Text

To the Editor:

The information already available has not been used to prevent HIV transmission among injection- drug users, and widespread HIV case reporting, however meritorious, will not improve that situation.

AIDS-surveillance reports present sufficiently clear and reliable information on the prevalence, incidence, and direction of the epidemic. They indicate a shift in primary risk behavior to injection-drug users, in whom approximately 50 percent of new infections are estimated to occur. (1) The disproportionate impact of the twin epidemics of drug use and AIDS on minority groups, particularly minority women, and among neonates is well documented. (2) On the basis of evidence that HIV is transmitted among injection-drug users through shared use of contaminated needles -- which, particularly in the United States, is necessitated by legal restrictions on drug paraphernalia -- European countries have liberalized paraphernalia policies as a specific HIV-prevention strategy for this group. However, driven by a war-on-drugs ideology rather than by public health and epidemiologic imperatives, the United States has not taken this simple step and thus has unleashed the epidemic among injection-drug users. (3)

This burgeoning pool of infected injection-drug users is concentrated in poor, urban, and predominantly minority neighborhoods, where the epidemic continues to worsen. Relatively small declines in the numbers of deaths from AIDS among members of minority groups (decreases of 2 percent among non-Hispanic blacks and 10 percent among Hispanics as compared with 21 percent among non-Hispanic whites) are a sad commentary on those left behind (4) despite general "advances." Unless rational policy changes allowing drug users to buy and carry their own injection equipment are enacted, HIV case reporting will have no effect on this population.

M. Daniel Fernando, Ph.D.
550 E. 16th St.
Brooklyn, NY 11226

References

1. Holmberg SD. The estimated prevalence and incidence of HIV in 96 large US metropolitan areas. Am J Public Health 1996;86:642-54.
Return to: Text

2. Gostin LO, Lazzarini Z, Jones TS, Flaherty K. Prevention of HIV/AIDS and other blood-borne diseases among injection drug users: a national survey on the regulation of syringes and needles. JAMA 1997;277:53-62.
Return to: Text

3. Fernando MD. AIDS and intravenous drug use: the influence of morality, politics, social science, and race in the making of a tragedy. Westport, Conn.: Praeger, 1993.
Return to: Text

4. Update: trends in AIDS incidence --United States, 1996. MMWR Morb Mortal Wkly Rep 1997;46:861-7.
Return to: Text

To the Editor:

In June of 1988, the Presidential Commission on the Human Immunodeficiency Virus Epidemic, established by President Ronald Reagan, issued its final report. Its first point states:

states:

> The term "AIDS" is obsolete. "HIV infection" more correctly defines the problem. The medical, public health, political, and community leadership must focus on the full course of HIV infection rather than concentrating on later stages of the disease. Continual focus on AIDS rather than the entire spectrum of HIV disease has left our nation unable to deal adequately with the epidemic. Federal and state data collection efforts must now be focused on early HIV reports, while still collecting data on symptomatic disease. (1)

Unfortunately, this sound recommendation was not acted on.

It is encouraging that many in the activist community and in academia are now supporting sound HIV policies. However, we should remember it was these same activists and academics who helped establish a very flawed policy in the first place. To continue to go to them for direction seems ill advised in the light of the admissions they now make regarding the sound HIV policy they fought against for so long.

Tom A. Coburn, M.D.
U.S. House of Representatives
Washington, DC 20515-3602

Shepherd Smith
Americans for a Sound AIDS/HIV Policy
Washington, DC 20041

References

1. Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, June 24, 1988. Washington, D.C.: Government Printing Office, 1988:87-9. (GPO publication no. 0-214-701:QL3.)
Return to: Text

The authors reply:

To the Editor:

The three letters in response to our article are representative of a growing consensus that a national system of HIV surveillance is essential for effective monitoring of and public health response to the HIV/AIDS epidemic. Our proposal for national HIV reporting will, of course, not solve all the perplexing public health and human-rights problems presented by the epidemic. HIV reporting is likely to demonstrate an increasingly disproportionate burden of infection among injection-drug users. In previously published research, we have strongly supported greater access to sterile injection equipment, as aptly suggested by Dr. Fernando. (1)

Drs. Solomon and Benjamin raise perhaps the most important intellectual challenge to a national system of named HIV reporting. Given the understandable concern about privacy, names should not be collected by the government unless it is necessary to achieve important public health purposes. Unfortunately, the data from Maryland do not demonstrate that a system of unique identifiers can provide accurate and reliable data. A recent evaluation of

system of unique identifiers can provide accurate and reliable data. A recent evaluation of the Maryland system supported by the Centers for Disease Control and Prevention found substantial limitations. (2) Of 9971 laboratory reports entered in the Maryland system from July 1994 through December 1996, 29 percent of the reports were missing a portion of the unique identifier, including 22 percent that were missing the social security number (the most specific component of the unique identifier). The Maryland system is also limited by a low rate of completeness of reporting (50 percent), an inordinate number of duplicate reports, and a lack of HIV-risk information. Finally, a unique-identifier system may create additional risks to privacy by increasing the number of surveillance registries. In order to collect follow-up epidemiologic information, private physicians have to maintain logs that link the unique identifier to a name-based medical record. These multiple registries in the private sector may defeat the privacy purposes behind unique-identifier systems.

Congressman Coburn and Mr. Smith support named HIV reporting but suggest that public health officials, community-based organizations, and scholars have lost any legitimate claim to leadership. This is an unfortunate implication coming from two leaders in American politics. Our positions on HIV policies are not formed by political or ideological beliefs. Rather, they are based on objective assessments of the science and of the public health, which necessarily must take account of the medical benefits to and the human rights of people with HIV infection or AIDS. It is not we who have changed, but the epidemic. Given the remarkable progress in medical treatment and a more humane social and legal response to AIDS, new ways of thinking about the epidemic become critically important. We need to create a national HIV-surveillance system that is scientifically sound and supported by the public it serves.

Lawrence O. Gostin, J.D.
Georgetown/Johns Hopkins Program on Law and Public Health
Washington, DC 20001

John W. Ward, M.D.
Centers for Disease Control and Prevention
Atlanta, GA 30333

A. Cornelius Baker
National Association of People with AIDS
Washington, DC 20005

References

1. Gostin LO, Lazzarini L. Prevention of HIV/AIDS among injection drug users: the theory and science of public health and criminal justice approaches to disease prevention. Emory Law J 1997;46:587-696.
Return to: Text

2. Evaluation of HIV case surveillance through the use of non-name unique identifiers --Maryland and Texas, 1994-1996. MMWR Morb Mortal Wkly Rep (in press).
Return to: Text

Please send me the article.

U.S. officials urge Illinois to require HIV reporting

BY JIM RITTER
HEALTH REPORTER

Federal health officials urged Illinois Monday to join 31 other states that require doctors to report names of people who test positive for HIV.

All 50 states require doctors to report to health departments the names of AIDS patients. Thirty-one states also require the reporting of people who test positive for HIV, the virus that causes AIDS.

The Illinois Public Health Department proposed mandatory HIV reporting in 1996 but backed off in the face of opposition from AIDS activist groups.

Officials from the Centers for Disease Control and Prevention urged HIV reporting during a news conference Monday at a conference on retroviruses and opportunistic infections. The meeting of HIV and AIDS researchers is being held this week at the Sheraton Chicago Hotel.

States have been recording the names of AIDS patients since 1981, with only one reported breach of confidentiality, the CDC said. Scientists have used those AIDS statistics to estimate the number of HIV infections.

But with new drug treatments, many people infected with HIV are not developing AIDS. Thus, AIDS statistics no longer provide a reliable way to keep track of the spread of HIV.

Health officials need better data "to monitor how well we're doing in preventing and treating HIV," said Patricia Fleming of the CDC.

AIDS activists worry about privacy. Mandatory HIV reporting would "discourage individuals from getting counseling and testing for fear of discrimination and breaches of confidentiality," said Mark Ishaug of the AIDS Foundation of Chicago.

The Chicago Health Department in the past has opposed HIV reporting, but it is rethinking its position, a spokeswoman said.

To determine whether HIV reporting discourages people from getting tested, the CDC studied nine states that have the requirement.

"Preliminary findings indicate that HIV reporting does not serve as a major deterrent to HIV test seeking among at-risk individuals," the CDC said.

The Illinois Health Department still plans to require HIV reporting, but it is waiting for the CDC study to be published, said spokesman Tom Schafer.

The state health department estimates that between 23,000 and 32,500 people in Illinois are infected with HIV. Many are not getting proper counseling on treatment options and notification of sex partners, Schafer said.

Under the department's plan, a public health official would visit and counsel a person who tests positive for HIV. The state also would notify the person's partners if the individual voluntarily provides names, Schafer said.

Name-calling

For minorities already distrustful of government, **HIV names reporting** could lead to fewer people getting tested for the disease

BY MUBARAK S. DAHIR

If whites with HIV shudder at the thought of Big Brother's punching their names into a database that tracks those infected, minorities with the disease are *really* running scared. Indeed, for some people, when it comes to mixing government and health, two words come to mind: Tuskegee experiment.

"The legacy of the Tuskegee experiment still reverberates," observes A. Cornelius Baker, the HIV-positive executive director of the National Association of People With AIDS in Washington, D.C., referring to a syphilis study conducted from 1932 to 1972 in which 400 black men in Alabama were denied treatment for the disease.

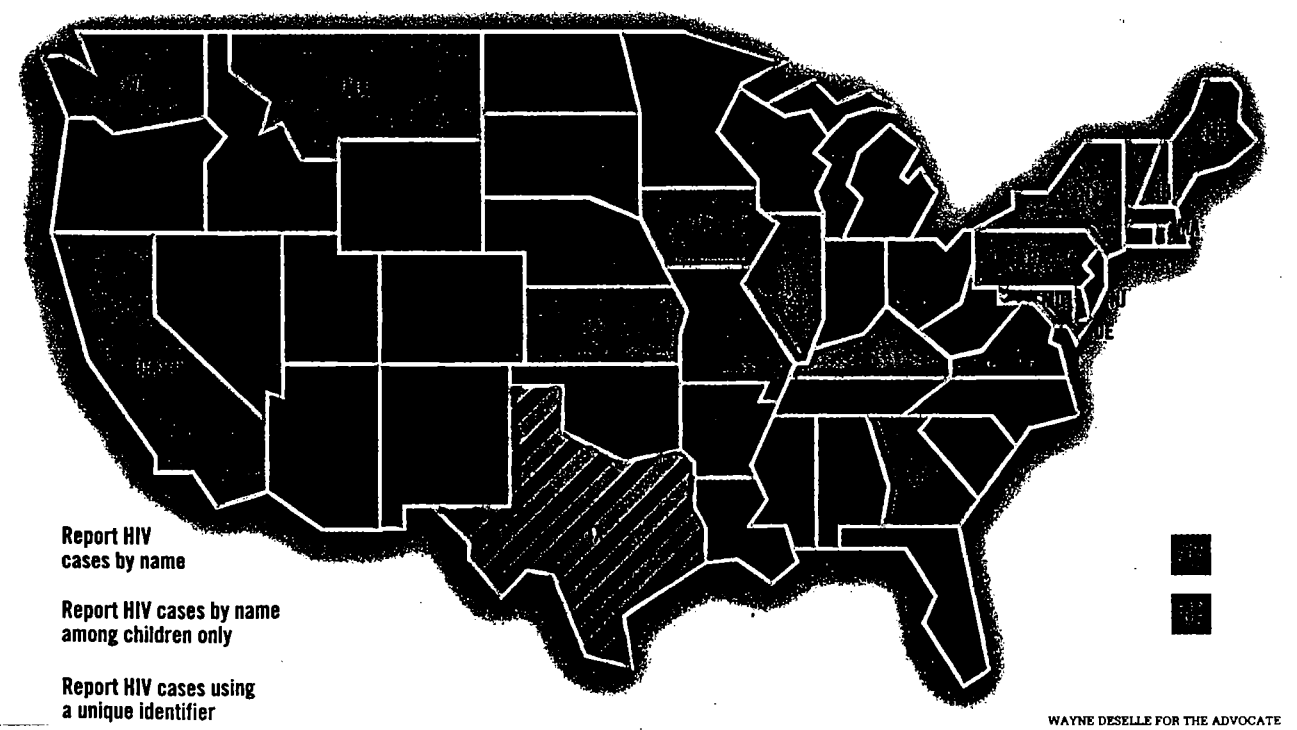
It wasn't until 1997, when President Clinton called the experiment "shameful" while addressing a group of the study's participants and their families, that the black community received an official government apology. "In the African-American community," says Baker, "trust is very low."

Sometime during the next couple of months, the Centers for Disease Control and Prevention in Atlanta will issue a set of recommendations on how state health officials should conduct the reporting of HIV cases. It is widely believed—and in many cases feared—that the upcoming CDC recommendations will push for a system of HIV reporting that requires states to collect names.

Meanwhile, Rep. Tom A. Coburn (R-Okla.) has introduced a bill in Congress that would not only mandate states to report HIV infections but also require partner notification and sexual-contact tracing. The bill would also give health care workers the right to deny care to anyone who refuses to take an HIV test.

The result, say leaders of several minority AIDS organizations, could be a new wave of people opting not to get tested. "Names reporting would have an absolutely detrimental effect in the Latino community," says Dennis deLeón, the HIV-positive president of the Latino Commission on AIDS in New York City. A December survey by

GETTING NAMED Twenty-eight states report HIV cases by name; these states account for only one third of the AIDS cases nationwide. (Source: CDC)



WAYNE DESELLE FOR THE ADVOCATE

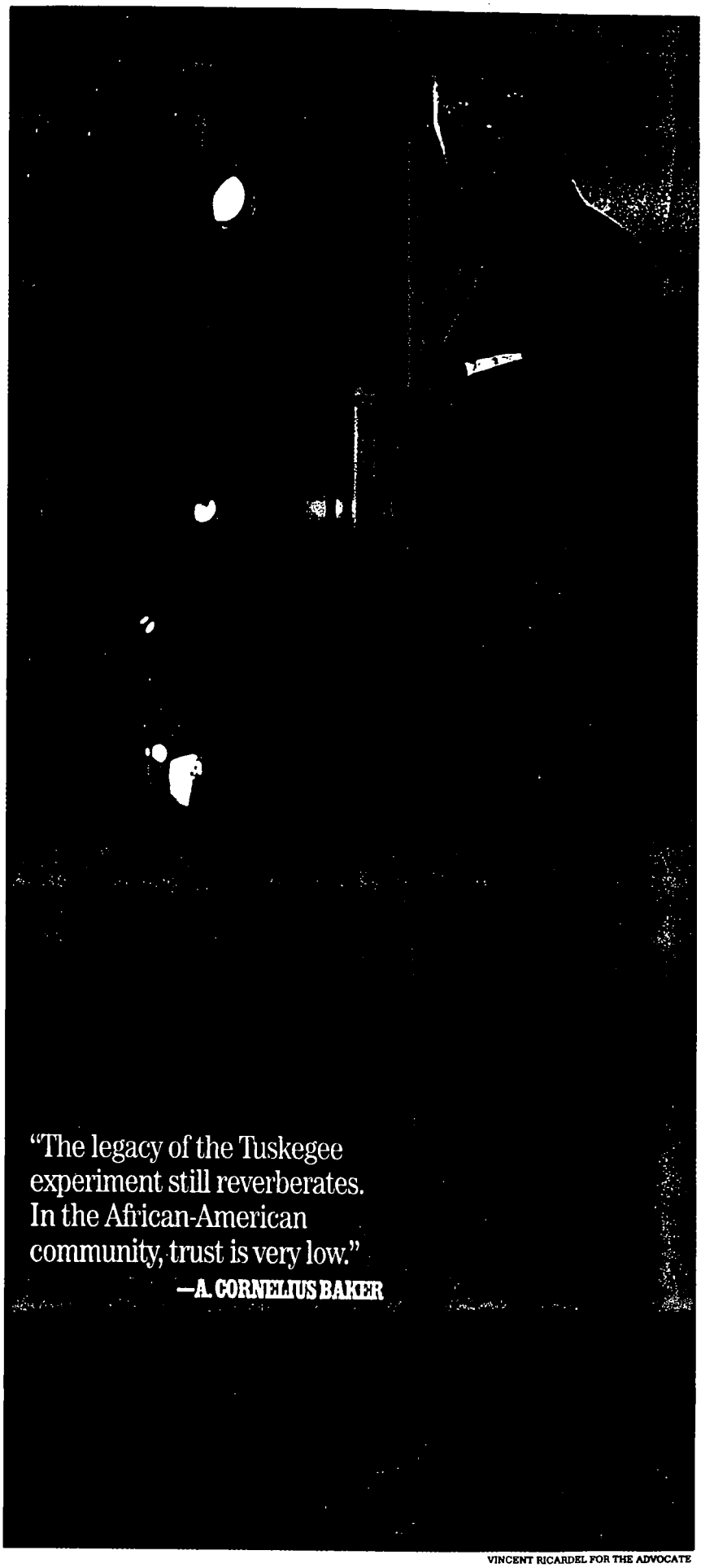
the commission found that while 88% of Latinos would take an HIV test if their names were not reported to any government agency, only 28% would do so if their names were reported in the event they tested positive. However, in a separate survey conducted by the New York City Department of Health, researchers found that only 22% of African-American and Hispanic participants would avoid being tested for HIV if their names were reported to public health officials.

"There is tremendous fear of government," warns deLeón, adding that the impact of names reporting in the Latino community could be felt in ways that the out gay community does not imagine. "In the gay community there is a culture of support" for HIV-positive people, he says. "But in the Latino community, people view an HIV-positive diagnosis as very isolating. So people would be much more cautious about their names getting out because of the cultural consequences."

In the book *Latino Gay Men and HIV: Culture, Sexuality, and Risk Behavior*, author Rafael M. Díaz, a professor at the Center for AIDS Prevention Studies at the University of California, San Francisco, argues that oppressive sociocultural factors and values such as machismo, homophobia, family loyalty, and sexual silence as well as poverty and racism already interfere with some gay Latinos' likelihood of practicing safer sex. He argues that prevention efforts need to break the "sexual silence" as opposed to being couched in imperatives and requests for compliance.

The combination of government distrust and fear of cultural exclusion runs high in many immigrant communities, adds Fernando Chang-Muy, former legal officer with the World Health Organization's Global Program on AIDS and now a law professor at the University of Pennsylvania. "In the Asian community everyone tends to know each other," he says. "So if a name gets out, it could result in almost anything, from being shunned in the community to deportation."

Noncitizens in the United States have one of two statuses: nonimmigrant or immigrant. Nonimmigrants, including students who could be in this country for as long as ten years to get a Ph.D., can be deported for having HIV, Chang-Muy explains. Immigrants—those with green cards, for example—cannot. ▶



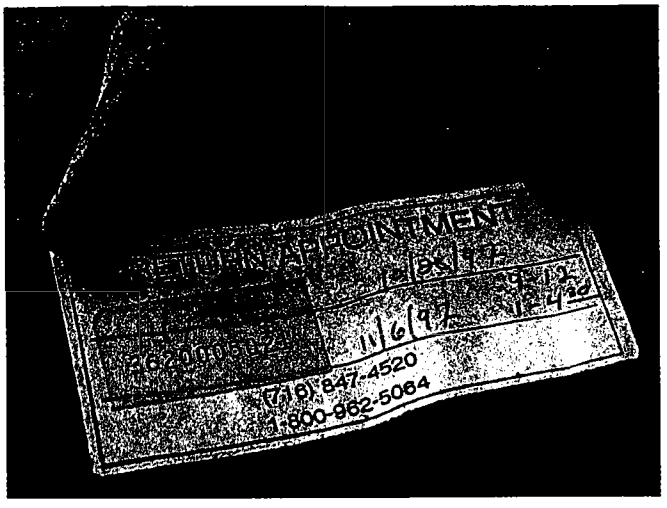
VINCENT RICARDEL FOR THE ADVOCATE

M. Saidia McLaughlin, a health educator with the Minority Task Force on AIDS in New York City, calls the threat of name disclosure from an HIV-positive test "a double whammy" for immigrants. First, there is the "general mistrust of the government having too much information on you." Second is the attitude that "no one is going to want to wreck their quest for citizenship."

Still, the idea of reporting HIV cases by name isn't new—28 states already do it, although these states account for only 33% of the nation's AIDS cases. Two additional states—Maryland and Texas—do HIV reporting through a secret code, or "unique identifier," which does not require collecting names.

All states require physicians to report cases of full-blown AIDS to public health departments. Most of those policies were adopted early in the AIDS epidemic, when an AIDS diagnosis meant that a patient didn't have long to live. Now, however, given the improved life expectancies for those with HIV or AIDS, fears of discrimination during that time are much more nagging and real, AIDS activists argue.

AP/WIDE WORLD PHOTOS



The result of names reporting, say some minority AIDS activists, could be a new wave of people opting not to get tested.

Still, arguments in favor of reporting HIV cases—though not necessarily by name—are plentiful. In fact, the nation's largest AIDS organization, the New York City–based Gay Men's Health Crisis, went on record in January saying such tracking is necessary because the epidemic is constantly changing. However, GMHC's policy statement calls for "a monitoring system with strong and enforceable privacy protections to prevent discrimination against people who are HIV-positive." It also calls for evaluation and implementation of a system of unique identifiers to be used in reporting.

Baker agrees that HIV reporting would yield better information on the state of the epidemic, including tracking changes in the virus within different populations. "In 1998 AIDS-stage illness isn't how we should be conceiving of this disease," he says, pointing out that the current system of AIDS reporting gives a ten-year-old snapshot of the epidemic (it takes roughly a decade between the time of infection with HIV and the onset of the illnesses that define AIDS).

Just about everyone concedes that, given new drug therapies such as protease inhibitors, the window between infection and illness is likely to increase. HIV reporting would allow experts to get a better picture of the most recent HIV trends: what populations are being hit hardest and where education and prevention efforts are most needed.

H. Alexander Robinson, president of the board of the National Task Force on AIDS Prevention, a San Francisco–based organization for gay men of color, says people concerned about HIV names reporting are equally concerned about access to care and want to see if the former would affect the latter. "The segment of the population that is already exposed to the public health care system may be more used to divulging important information about themselves in order to get assistance," he says. "So the issue for them when it comes to names reporting is this: What's the payoff? If I give my name, will I be assured access to health care?

"Sure, names reporting would give us a better picture of HIV, but will that picture affect how we allocate funds to those who most need them?" asks Robinson. McLaughlin also questions how the newly gathered information would be used to help the most disadvantaged people in the health care system—by and large, minorities and immigrants. "The way our health care system is set up, minorities are already disadvantaged when it comes to access to care," McLaughlin says. "So some people might look at this as just another layer to a long list of very oppressive ideas in the health care system."

Meanwhile, some activists believe the CDC has been quietly trying to get state health officials used to the idea of reporting HIV cases by name. CDC officials deny this, saying that while names reporting has been the most reliable means of surveillance to date, it is still evaluating other means. Last September the CDC sent out a survey to all state health departments to determine "[w]hat steps *must* be taken...to allow for...reporting of persons (by name) with laboratory evidence of HIV infection." The CDC is convinced of the need for HIV reporting by some means, says John Ward, chief of AIDS/HIV surveillance at the CDC. A September article in the CDC's *Morbidity and Mortality Weekly Report* noted that, in light of the decline in AIDS cases, HIV reporting would provide a better picture of the epidemic. An October article in *The New England Journal of Medicine*, coauthored by Ward, Baker, and Lawrence O. Gostin of the Georgetown University Law Center, discussed HIV reporting by name and other means.

Ward says he hopes that the CDC recommendations for HIV reporting will be finalized by the end of the year and that all states will be doing HIV reporting by early 1999: "There is no question in my mind that, sooner or later, HIV surveillance will happen." ■

CDC Meeting

2/16/98

Deborah VmZ
Seth K
Mike Shriver
Michael A
David H
David Harvey
Earnest
Ron V
Helene
Julie S
Julio
Migalena
Jeff

John Ward
Rob Johansen

John Ward : working for 1 yr.

Background
Case Definition
Surveillance Practices

Criminal penalties for unauth access

CDC wants guidelines by mid-June

raise the bar
still holes in data - caution about talking about $ funding
data points

Why 75 not 80
how fill holes
other data / data points /

(15)

NATIONAL NONGOVERNMENTAL PARTNERS BRIEFING
FEBRUARY 17-18, 1998
Executive Park Building 24 Conference Room

February 17, 1998

9:00-9:30	Welcome	Helene Gayle
	- National Center for HIV, STD, and TB Prevention - CDC HIV allocation and location (who gets what)	
9:30 - 11:30	DHAP- Intervention, Research, and Support Short Presentations and Discussion	David Holtgrave
	- CAPNP — Fred Martich - BIRB — Lynda Doll - PERB — Huey Chen - TICB — Sara Thrift - TSSB — Sue Dietz - International — Victor Barnes	
11:30-11:45	Break (Order lunches)	
11:45-12:00	DASTLAR (Labs)	Harold Jaffe
12:15-1:00	Lunch	
	- Youth Issues — Chad Martin - Open Discussion	
1:00-3:00	DHAP- Surveillance and Epidemiology	Kevin De Cock Rob Janssen
	- Surveillance — John Ward - Prevention Services — Richard Steketee - Epidemiology — Jeff Efird - International — John Narkunas - Data Management — John Karon	

NATIONAL NONGOVERNMENTAL PARTNERS BRIEFING
FEBRUARY 17-18, 1998
Executive Park Building 24 Conference Room

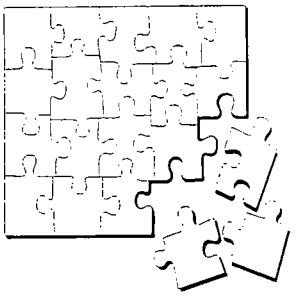
February 17 continued:

3:00-5:00	Discussion	Helene Gayle
	- Division Priorities - Accountability issues - HHS agency collaboration - Emerging issues	
5:00	Wrap-up	

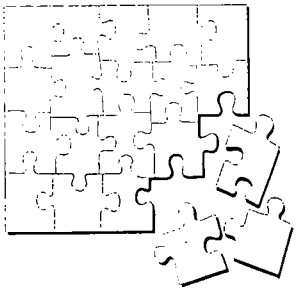
February 18, 1998

9:00 - 9:15	Welcome, Overview, and Discussion	Ron Valdiserri
9:15- 9:30	Office of Communications	Melissa Shepherd
	- Role of OD Communications - National AIDS Clearinghouse	
9:30-10:00	STD HIV Link	Judy Wasserheit
10:00-11:00	Division of Adolescent and School Health (DASH)	John Moore/Lloyd Kolbe
11:00-11:15	Division of Reproductive Health (DRH)	Dora Warren
11:15 - 11:30	Break (order lunch)	
11:30 - 12:00	Community Planning Update	Mary Willingham
12:00 - 1:00	Lunch	
1:00 - 3:00	Open Discussion	David Holtgrave
3:00	Wrap-up	

Division of HIV/AIDS Prevention – Intervention Research and Support
(Draft) Strategic Factors List
January 1998



- Clarifying and Further Developing our National Strategy for HIV Prevention
- Showcasing our HIV Prevention Successes
- Preparing the Community Planning Process for Success over the Long Haul
- Reassessment and Strengthening of HIV Prevention Efforts among Women, Communities of Color, and Gay Men
- Strengthening HIV Prevention Efforts for Each and Every Generation of Young People
- Prevention of HIV Infection Due to Drug Injection Behaviors (Given Current Societal Constraints)
- Systematic, "Bidirectional" Technology Transfer
- Primary HIV Prevention in an Era of Treatment and Technologic Advances
- Accounting for the Costs and Consequences of HIV Prevention Programs: A National, Quantitative Perspective
- Removing Barriers to the Implementation of Effective HIV Prevention Programs



Strengthening connections to care
coordination with STD + MCH

HIV INFECTION SURVEILLANCE
Feb-98

Name-Based	Non-Named Unique Identifier	Pending
Alabama	Maryland****	Alaska
Arizona	Texas***	California
Arkansas		Connecticut*
Colorado		Delaware
Connecticut*		Georgia
Florida		Hawaii
Idaho		Illinois
Indiana		Iowa
Louisiana		Kansas
Michigan		Kentucky
Minnesota		Maine
Mississippi		Massachusetts
Missouri		Montana
Nebraska		New Hampshire
Nevada		New York
New Jersey		Oregon**
New Mexico		Pennsylvania
North Carolina		Puerto Rico
North Dakota		Rhode Island
Ohio		Vermont
Oklahoma		Virgin Islands
Oregon**		Washington****
South Carolina		District of Columbia
South Dakota		
Tennessee		
Texas***		
Utah		
Virginia		
West Virginia		
Wisconsin		
Wyoming		

****

All states report AIDS cases by name at the state/local level. States do not total 50 since some states are listed in multiple columns

* Requires reports of HIV infection in children < 13 years by name, Reports of HIV infection not required for adults/adolescents 13 or more ears of age

** Requires reports of HIV infection in children < 6 years by name

*** Requires reports of HIV infection in children < 13 years by name. Requires anonymous reports for adults/adolescents 13 or more years of age

**** Requires reports of symptomatic HIV infection by name

Daniel C. Montoya
11/05/97 04:40:47 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc: Sandra Thurman/OPD/EOP, Todd A. Summers/OPD/EOP
Subject: trying a different format - surveillance discussion papere

FYI -

dcm

---------- Forwarded by Daniel C. Montoya/OPD/EOP on 11/05/97 04:38 PM ----------

terje @ worldnet.att.net
11/05/97 11:54:00 AM

Record Type: Record

To: Daniel C. Montoya

cc:
Subject: trying a different format - surveillance discussion papere

HIV name reporting: the wrong debate

Increasingly a discussion within the AIDS community (and externally, witness Rep. Coburn's efforts) is focusing on the question of adoption of a names-based reporting system for HIV infection. A number of national organizations, including the Council of State and Territorial Epidemiologists (CSTE) and the National Association of State and Territorial AIDS Directors (NASTAD) have taken positions in favor of a national standard of named HIV reporting. There are indications that the Centers for Disease Control and Prevention (CDC) will soon undertake efforts to encourage named reporting in all 50 states. Perhaps not surprisingly, a polarized debate seems to be developing around the question, with many community based groups taking a hard line against any form of named reporting, arguing instead for HIV reporting using unique identifiers (if there is to be any HIV reporting at all).

I would submit that the polarized debate taking place is counter-productive and, moreover, misses the point about what it will really take to implement necessary steps to truly understand the extent, distribution and direction of the continuing HIV epidemic. To that end, I offer this (high opinionated) discussion paper to the debate.

Why the debate? What are the changes propelling it?

There is widespread agreement that our current national surveillance system woefully inadequate and uneven. Diagnosed AIDS is reportable by name in all 50 states, while HIV infection is currently reportable by name in slightly over half the states - although many of the largest states with high HIV prevalence (including California, New York, Massachusetts, etc) do not have HIV reporting.

While reliance on AIDS reporting was always inadequate (due to the long lag time between infection and clinical illness), recent developments in treatment which greatly delay disease progress accentuate these inadequacies. Reported numbers are falling significantly, but this is largely a result of changes in the treatment of HIV infection instead of real changes in incidence. The old case definition is increasingly meaningless in light of the changes in the reality of the disease itself. Our reliance on AIDS reports as the primary data about the epidemic has always been problematic - now it is so irrelevant that something must be done to improve it. Our ability to understand this epidemic and to make good decisions about the focus of prevention and care efforts relies on correcting this situation.

In 1993, an attempt to recognize the changes going on in the disease was made when the case definition was expanded to include low tell cell counts. Some would argue that HIV reporting is simply a recognition of the changes in the treatment field where treatment of HIV infection, rather than AIDS symptoms, is the new health paradigm.

There are three main arguments that are being cited by some advocates of named reporting (please note that not all advocates cite the all three arguments, or put the same spin on any of these arguments. My apologizes to those whose arguments I have simplified, misstated, or bastardized - I am reflecting them as best I have heard them).

1.) Because of the inadequacy of current reporting systems, it is necessary to move to HIV named reporting in order to more fully capture the HIV epidemic. This includes the need for better data for service and prevention planning, as well to prevent the lower numbers from lulling the public and policy makers into false complacency. How can we retain and increase resources if the public thinks AIDS is going away? Whatever the drawbacks of HIV named reporting may be, the data we receive from it will undoubtedly be better than what we currently have.

2.) For too long, AIDS/HIV has been treated differently than other diseases of public health significance and this has, according to the argument, hampered our ability to effectively fight the epidemic using the best tools that public health has to offer. By treating it this way, we have heightened the stigma and fear, instead of mainstreaming and normalizing AIDS/HIV. While this may have been understandable in the beginning (where social stigma was much higher than it is today. Now that better treatment exists, it is time to break down that stigma by ending any kinds of "AIDS exceptionalism." A good place to start is by dealing with the way we treat issues of reporting

to public health officials. Lack of HIV reporting is a remnant of the paranoia (not always unjustified) of the early days of the epidemic - but now we have to move past policies made for and in 1985.

3.) Named reporting is important in order to ensure that all people with HIV are offered access to needed medical and social services. Now that potentially effective treatment exists, it is imperative that we contact all people with HIV to ensure they know about it and receive assistance in accessing the best services available. In addition, some argue that named reporting is essential to development of suitably aggressive programs to locate and bring into testing/ treatment/prevention services the partners of those infected. Only by doing so will we be able to offer appropriate early intervention (possibly including PEP) to the newly infected, and thus stem the further spread of the epidemic and/or disease progression in the infected.

In addition, a fourth argument (with two variations) is likely to emerge in the near future..

4.) In light of the Chautauqua County and Ohio incidents and the surrounding publicity, there is likely to be a widespread public demand for increased reporting, testing and partner notification. Some would argue that we cannot ignore such public sentiment, and therefore should implement named reporting. Others in the public health community worry that if we do ignore the weight of public opinion, we only increase the gulf between a public health/AIDS elite and the community at large - an invitation to disaster with the adoption of even more restrictive legislation and bad policies. In such a scenario, named reporting is a necessary step (evil or good) to ward off far worse consequences.

HIV name/ unique identifier reporting - why neither gives us what we need

We must start with a basic understanding of a crucial difference between AIDS and HIV reporting. AIDS reporting was historically based on a single incident - the diagnosis of an AIDS defining condition, such as an opportunistic infection or (in recent years) a t-cell count under 200, indicative of immune system suppression. In most (but not all) cases, such a diagnosis is driven by a health occurrence that drives a person to seek out medical care. With a relative degree of predictability, a person experiencing health declines will seek out medical care (although questions of access to care and awareness of risk clearly delays the speed at which some people and populations have, in fact, entered systems of care, resulting in diagnosis and reporting delays for those individuals and populations). With a ton of caveats attached, it can be said that AIDS reports represent a group of people who have experienced a relatively similar health event - and therefore the number has (or had) some relatively uniform meaning. It could be predicted that a relatively high percentage of people who have experienced the health events will seek care and be reported to the local/state Department of Health.

Testing for HIV represents a much wider potential range of health events. Some positive tests take place when someone is entering an emergency room with PCP, while others take place in someone who is entirely asymptomatic but concerned about their past risk. Given the long time frame for disease progression, it is very difficult to accurately say what a positive test means about the health status of any individual. There is a wide range of acceptance of testing in different communities, and a wide range of precipitating events that may drive someone to testing. Unlike AIDS reports, which reflect a relatively defined and limited stage of illness, HIV reports have a much less specific meaning. The number of people testing positive therefore represents simply people who were aware of their own risk, connected to health care, and concerned enough to seek out or accept testing. These factors may be impacted by a variety of highly localized or individualized factors: local outreach or education efforts, health care provider attitudes, local media coverage, health insurance coverage, peer norms, and personal risk perception.

Because acceptance of testing is not universal, and because timing of testing in not uniform, it is far harder to state definitively what HIV reporting tells us, and severely limits how we can use the information.

HIV reporting does not tell us how many people are living with HIV - in the country or in any particular area. It only tells us how many people have taken the test and come back positive.

HIV reporting does not tell us which populations are experiencing new infections. Rather it tells us which infected populations are coming forward for testing. It does not state how recently they were infected or what percentage of a risk population is positive. It is highly subject to artifacts of testing systems - for example, if a clinic with testing outreach were to open in a previously under-served neighborhood with a particular ethnic concentration, it is likely that reports for that group would increase. (Similarly, a drop might be seen if that program lost funding). To presume that either situation reflects new infections would be erroneous..

HIV reporting tells us nothing about the extent or spread of HIV in populations that are not being tested. To rely on HIV data for decision making about prevention or care efforts is to risk being misguided by biases inherent in any voluntary system with uneven levels of testing acceptance. In the real world, HIV reporting is likely to bend decisions in favor of those populations that are already most aware of HIV and already accessing HIV services. Populations with inadequate access to treatment and prevention services will continue to be undercounted in HIV reporting, accentuating pre-existing inequities. Rather than serving as an early warning system, testing will only pick up any significant trend once people in a community are already aware enough of risk that they are seeking testing.

The arguments against named reporting (and some potential responses)

Those rallying around opposition to named reporting focus primary on the argument that named reporting will drive people away from systems of testing. According to this argument, people in affected communities have such strong distrust of government that the knowledge that their name might be put on a government list might keep them from getting tested or seeking medical care if they are infected. At a time when there is a huge imperative to encourage people to know their status and seek early treatment, anything that discourages these things is a problem.

(A second fear raised by many people is that once the names are collected, discrimination or punitive measures against those people will take place. I will discuss this potential concern in the next section, although it is important to note that this has not been born out by actual experience.)

The evidence of disincentive to testing is somewhat mixed and quite limited - experts on both sides of the question debate the meaning of one study versus another, but there has yet to be a conclusive examination of all of the data - for example, comparison of acceptance of testing among different populations in parallel states with and without named reporting. The MESH study results (mentioned in Atlanta as nearing completion) should be carefully examined. Based on the data that I have seen, it seems likely that the net effect of named reporting is a slight but measurable drop in testing, and that this drop is most likely to be seen among relatively well educated gay men who distrust the government.

It is important to remember that in nearly 30 states, people with HIV already live with named reporting. Quite simply, the sky has not fallen in those states.

Named based AIDS reporting has been widely accepted by the same advocacy community that so vigorously opposed HIV named reporting. It appears to be accepted by people living with AIDS, and there is little evidence that it is driving people away from care. Perhaps it can be argued that for symptomatic people, the option of not seeking care is less viable than it would be for asymptomatic HIV+ people, but it seems someone absurd to believe that reporting drives one group away one group(HIV+) but not another (AIDS).

I also want to raise the question: does the loud opposition to reporting become a self- fulfilling prophecy? After hearing all kinds of dire warnings about how people at risk can't trust the government, doesn't that, in fact, contribute to the environment of distrust that exists. If we have a protracted national and state-by-state debate about reporting, will that debate itself serve to drive people further away from testing and care.

It is also important to recognize that in many other ways, people with HIV have no choice but to have their names reported to the government. Anyone who relies on Medicaid, Medicare, AIDS Drug Assistance Programs, public health clinics, federal and state disability

programs, insurance continuation programs, some Ryan White activities, etc., already has no choice but to have their HIV status made known to the government. The double standard of confidentiality for the well off and government access for the poor should not be forgotten.

The potential drawbacks and risks of named reporting

Having recently moved from a state (Vermont) without HIV named reporting to a state (Colorado) with a long established named reporting system, I have several concerns based on anecdotal observations about the different systems.

One of my greatest concerns is the way in which numbers are interpreted and presented. Quite simply, I am not impressed with the way these numbers are used.

I have repeatedly heard people who should know better (state and county health officials, AIDS service providers, community based organizations, consortium members, community planning group members) refer to the numbers reflected by HIV reports as representing the total number of HIV infected people within a jurisdiction, or as being reflective of new infections, or as a reliable predictor of future infections. Rarely, if ever, are the limitations or true meaning of the data discussed. Unfortunately, this does not contribute to enhanced public understanding of the epidemic, nor to better planning for services or prevention.

Similarly, I have been part of review panels for CDC prevention grants, HRSA Title I and SPNS grants, and a number of foundation grants. Unfortunately, in these settings I have seen little creative use of HIV data to guide decision making and priority setting. The data doesn't live up to the promises made for it.

I also have concerns that there are few safeguards about how the data may be used by those collecting it. For example, I was surprised at one local meeting when officials from the county Health Department indicated that they had matched arrest records from a local gay cruising area with HIV testing data. Although they had data on a small percentage (about 10%) of the arrestees, they announced that the seroprevalence in the park was a certain number. Quite simply, this is an epidemiologically invalid interpretation of these numbers, and certainly would not do much to engender trust among the risk population about the way their confidential data is used. The temptation to play with numbers must be recognized and tempered by strict guidelines about the uses of the data and the way it can and cannot be matched to other data sets.

Similarly, we must acknowledge that the potential exists for policy makers (especially legislators) to demand that the collected names be used in ways that many in the public health and AIDS communities would find inappropriate. This prospect cannot be dismissed out of hand - think, for example, of the success that Jesse Helms and others have had in inserting spousal notification, emergency responder

notification, sexual assault victim notification, and similar measures into federal legislation. How confident are we that we can successfully fight off mandatory partner notification, or legislation targeting particular professions (health care workers, child care providers, etc.)? While I do not consider these likely, it must be acknowledged that they are possible? Are we prepared to respond to them?

I believe the most damning argument against named reporting is simply that it will not produce what is promised in way of a better understanding of the epidemic.

While I believe that opponents of named reporting are sincere in their concerns, quite candidly it strikes me as a knee-jerk reaction based on old realities and exaggerated concerns about confidentiality and disincentives to testing/treatment. Similarly, I believe that advocates for named reporting are looking at a simplistic solution to a complex problem, and that they are not addressing the real question of what it will take to truly understand where the epidemic is going.

What would a comprehensive HIV surveillance system look like?

The CDC Advisory Committee on the Prevention of HIV Infection has stated that the goals of HIV/AIDS surveillance are:

1.) To target primary and secondary prevention
2.) To evaluate the efficacy of prevention activities
3.) The determine eligibility for government resources for services for HIV- infected persons
4.) To project resources needed to provide care and prevention interventions
5.) To educate the public about the scope and impact of the HIV/AIDS epidemic

I would argue that, in order to meet these goals, we need data far more than we need names. Case reporting (named or unique identifier) is the most traditional public health effort to monitor an epidemic. It is also the least imaginative and least well-suited for an on-going epidemic of the complexity of HIV/AIDS. I believe we must challenge the public health community to develop much more innovative methods to provide needed information.

I find it highly ironic that the CDC is prepared to push for named reporting at this point, when two years ago they rolled over and played dead when the Survey of Child Bearing Women, a blinded seroprevalence study done in 46 states, was taken away. It is precisely this kind of study that is needed to enhance our understanding of the epidemic for both care and prevention services. Reinstatement of the SCBW should be a major priority of enhanced surveillance avtivities.

While I am not a trained epidemiologist, I would like to offer some ideas (some close to what is being done, some much further out of the box) about what elements of an innovative national surveillance program might look like. I don't pretend that this is a comprehensive list, but rather one that gives some picture of the kind of activities

that would, taken together, provide decision-makers and communities with the information they need to make informed decisions about resource distribution. Some of the ideas I have suggested make the assumption that HIV reporting is in place.

As stated above, reinstatement of the SCBW should be a high priority for all of us. This population based study provided incredibly valuable information about the spread of HIV among women of child bearing age.

Similarly, other blinded seroprevalence studies (part of the "family of surveys") that are currently conducted in sexually transmitted disease clinics and drug treatment facilities should be greatly expanded to reflect greater geographic scope and range. While economic consideration may limit how far it can be expanded, a system of near universal blinded screenings in these settings would provide a highly sensitive surveillance tool for the populations that use these resources. In addition, we should look for other settings where such blinded studies can appropriately be conducted.

Several years ago, there was serious discussion of a national door to door survey that involved blinded testing. This idea should be resurrected. Especially with the availability of newer, less intrusive collection techniques, there may be a higher rate of acceptance of testing than ever before. Such a survey could collect important data about the geographic, demographic and behavioral factors relating to infection. Oversampling could be used with key populations and in key localities. Repeating the survey on a regular basis would provide valuable information about incidence.

Sentinel studies should be strengthened in areas where there are particular concerns. Sites around the country serving important demographic or behavioral populations should be selected, and monitoring HIV infection rates by the clients of such facilities on an on- going basis provides valuable information. Outreach testing in key locals (shooting galleries, bars, bathhouses, homeless clinics, low income neighborhoods, migrant worker camps, etc.) should be enhanced and incorporated in these sentinel studies.

Increasingly, we need to use technology that allows some estimation of how recent or distant an infection is: measures such as CD4 counts and natural viral development markers can help "date" new infections among those testing positive.

Collection of data on all HIV testing, not just positive tests results. Knowing how many people in any particular population test positive without knowing how many people in that group were tested is of limited use. Being able to have data about the percentage of people in any particular population seeking testing who have tested positive would be valuable, but at the moment that data is only widely available for publicly funded alternative test sites (and, in some cases, other STD, prison and similar clinics). According to CDC, only 15% of positive tests come from the publicly funded ATS facilities, while 52% were in private physicians, clinics and hospitals. It would

not be necessary to collect names in order to obtain this kind of data.

Behavioral surveillance should be given greater emphasis, including greater use of the sexual behavioral elements in the BRFS and the YRBS, increased use of the behavioral information being collected in countless local prevention and service products, and selective studies to measure the prevalence of HIV risk behaviors in key populations. These studies should be matched with local data about HIV prevalence/incidence and solid scientific information about transmission efficacy.

Priority should be given to development of mathematical modeling techniques that allow more accurate estimation of HIV in various communities, and assistance in applying these techniques in various environments. The CDC should commit itself to analyzing data annually and releasing estimates of HIV prevalence and incidence based on that data and these models.

Enhanced technical assistance programs for health departments, community planning groups, planning councils and consortia are sorely needed. Data is currently poorly used in most places, and much more effort needs to be made to help key players understand and effectively utilize this data.

This is by no means a comprehensive list, but instead serves, I hope, to stimulate thought and discussion on alternative or complements to HIV reporting that can help achieve our goal of having adequate information to shape our prevention and care efforts.


110512A8.TX 110512A9.TX

Message Sent To:

lsbell @ hugheshubbard.com @ inet
harndc @ aol.com @ inet
bigbob411 @ aol.com @ inet
katgerus @ sprynet.com @ inet
RAPANUIJER @ aol.com @ inet
altaperez @ aol.com @ inet
debaids @ isdn.net @ inet
mojo1025 @ aol.com @ inet
gaylesmed @ aol.com @ inet
shenovice @ aol.com @ inet
ctroupe @ services.state.mo.us @ inet

Qs and As for use with the Media
Anticipated in response to *MMWR* on evaluation of Non-Named Unique Identifier Systems

Q1 What did this evaluation of UI-based HIV surveillance find?

A1 The evaluation revealed that social security number based UI systems do not provide reliable data for directing prevention and treatment and may not reduce confidentiality concerns. Specifically, the SSN based UI systems are limited in performance as follows:
* Completeness of reporting for the UI system (26 to 52 percent) was far less than for name-based HIV surveillance systems (79 to 90 percent).
* Many members of the affected communities may not have SSNs.
* Health departments could not reliably eliminate duplicate case reports from the UI systems.
* The UI-based systems in these states did not request HIV risk information on the initial case reports. Although risk information may be available on follow-up with providers, these UI-based systems greatly increase the complexity of follow-up necessary to complete basic risk information.
* The UI-based systems precluded the integration of HIV surveillance data with other relevant name-based public health information systems (e.g. tuberculosis).
* UI-based systems may not diminish the risk of breaches in confidentiality when providers are required to maintain logs to match UIs with patients, because this approach increases the number of lists of HIV infected people that could be disclosed in a breach of confidentiality.

Q2 Why is HIV surveillance needed?

A2 There is an urgent public health need to implement HIV surveillance. In comparison to AIDS surveillance alone, HIV surveillance provides population-based data not affected by treatment advances. In addition, HIV surveillance provides more timely information than AIDS surveillance about the changing demographics of the epidemic. HIV surveillance can also offer a more complete assessment of the burden of pediatric HIV infection and effectiveness of prevention interventions to reduce perinatal HIV transmission.

Q3 Will CDC be recommending name-based HIV surveillance?

A3 CDC has not finalized its policy on HIV surveillance. CDC recommendations will be published in draft form in a guidance document that will be released in the next few months. Because surveillance data are so critical to prevention and treatment services, (these data translate into prevention, services, and care for people with HIV/AIDS at national, state, and local levels) CDC must recommend approaches based on their performance. Any potential HIV surveillance system will need to meet very specific performance criteria for effectiveness and security. The upcoming guidance will specify these criteria.

Evaluation of HIV Case Surveillance Through the Use of Non-Named Unique Identifiers--Maryland and Texas, 1994--1996

CDC Evaluation of Unique Identifier-Based HIV Surveillance Systems Finds that Current UI Systems Provide Limited Data and May Not Reduce Confidentiality Concerns

This article reports findings from a three year evaluation of HIV surveillance systems which utilize unique identifiers (UI) as the basis for HIV case reporting. Currently, 31 states conduct name-based HIV surveillance as an extension of their AIDS surveillance systems (3 for pediatric HIV infection only). Because of concerns about name-based reporting, CDC has worked with Maryland and Texas since 1994 to evaluate HIV surveillance systems which use a UI, based primarily on social security number, to report HIV cases. The evaluation revealed several problems with these UI systems, including a high number of reports with incomplete codes (approximately 30-40%), low rates of completeness in reporting (approximately 25-50% complete), difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data in this system. Additionally, a UI-based system may not reduce the potential risk for a breach of confidentiality when providers are required to maintain lists to link the UI with patients because this approach increases the number of lists that could be disclosed in a breach of confidentiality.

Barawan Somali Refugees — Continued

Because some Barawan Somali refugees were infected with both helminthic and protozoan pathogens, the interim recommendation for mass pre-embarkation therapy with 3-day mebendazole was changed to single-dose albendazole (400 mg per kg of body weight) for all persons except pregnant women.[1] This approach was considered preferable because of the high prevalence of mixed intestinal parasites, the low cost of albendazole, and the ease of single-dose therapy before departure (*4–6*). The optimal choices of agent(s) and duration of therapy for mass treatment of intestinal parasites among refugee populations remain to be determined.

The program of enhanced screening for and management of infectious diseases among this vulnerable refugee population enabled the implementation of population-based interventions before members of this group dispersed to multiple locations in ≥20 states. CDC is notifying health officials in the states in which refugees are being resettled of the results of the pre-embarkation medical screening and treatment. CDC also is working with IOM and state refugee health programs to develop a shared database of refugee medical screening results.

References

1. Slutsker L, Tipple M, Keane V, McCance C, Campbell CC. Malaria in East African refugees resettling to the United States: development of strategies to reduce the risk of imported malaria. J Infect Dis 1995;171:489–93.
2. CDC. Malaria in Montagnard refugees—North Carolina, 1992. MMWR 1993;42:180–3.
3. Gyorkos TW, Frappier-Davignon L, MacLean JD, Viens P. Effect of screening and treatment on imported intestinal parasite infections: results from a randomized, controlled trial. Am J Epidemiol 1989;129:753–61.
4. Raccurt CP, Lambert MT, Bouloumie J, Ripert C. Evaluation of the treatment of intestinal helminthiases with albendazole in Djohong (North Cameroon). Trop Med Parasitol 1990;41:46–8.
5. Pungpak S, Singhasivanon V, Bunnag D. Albendazole as a treatment for *Giardia* infection. Ann Trop Med Parasitol 1996;90:563–5.
6. Hall A, Nahar Q. Albendazole as a treatment for infections with *Giardia duodenalis* in children in Bangladesh. Trans R Soc Trop Med Hyg 1993;87:84 6.

[1]Albendazole is currently approved by the Food and Drug Administration for treatment of neurocysticercosis and hydatid disease.

Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers — Maryland and Texas, 1994–1996

Notifiable disease reporting laws or regulations in states and territories require reporting of acquired immunodeficiency syndrome (AIDS) cases, including patient and physician names, to state or local health authorities. As of January 1, 1998, a total of 31 states were conducting name-based human immunodeficiency virus (HIV) case surveillance by using the same methods as surveillance for AIDS. However, because of concerns about name-based HIV surveillance, Maryland and Texas implemented HIV surveillance using non-name unique identifiers (UI)*. This report summarizes a 3-year collaboration by CDC and these states to evaluate UI surveillance for HIV infec-

*Reporting in Maryland is exempted for nonstate residents; persons who are tested at anonymous test sites; are blood, semen, or tissue donors; and participants of certain research projects. No exemptions to reporting exist in Texas.

HIV Case Surveillance — Continued

tion; the findings indicate some limitations to the use of a Social Security number-based UI for HIV surveillance.

In both Maryland and Texas, UI surveillance for HIV was implemented in early 1994, and both used the same 12-digit numeric UI code (comprising the last four digits of the patient's Social Security number [SSN], six-digit [month/day/year] date of birth [DOB], one-digit code for race/ethnicity, and one-digit code for sex). HIV-infection reports included residence data, diagnosing facility, and date of test, but did not include mode of HIV exposure. In both states, UI HIV surveillance databases were maintained separately from name-based AIDS surveillance databases.

Evaluation criteria included the proportion of reports with full UI codes, timeliness and completeness of HIV reporting, and potential for matching the UI-based case reports to alternate databases. In Texas, selected HIV reports also were evaluated for ability to follow back UI reports to patient records; in Maryland, provider compliance with maintaining patient surveillance logs was assessed. During July 1994–December 1996, Maryland reported 6412 AIDS cases and received 9971 HIV-infection reports, and Texas reported 12,041 AIDS cases and received approximately 23,000 HIV-infection reports.

Maryland

In 1993, the Maryland legislature mandated UI reporting of both positive HIV tests and patients with CD4+ T-lymphocyte counts of <200 cells/μL (CD4+)[1]. Health-care providers requesting HIV or CD4+ tests are required to construct the UI code for each patient, include the code on the laboratory slip, and record it in a surveillance log that matches the UI to patient identifiers (e.g., medical record number, patient name, or other patient code) for purposes of case investigation and follow up. Laboratories licensed by Maryland are required to submit the UI-based reports to the state health department through the local health departments.

Of 9971 HIV-infection reports entered during July 1994–December 1996, all UI elements were present for 7119 (71%) (Table 1). Element-specific presence ranged from 78% (SSN) to 98% (DOB and sex). The proportion of reports with full UI increased during July 1994–June 1996, and declined slightly during July–December 1996. The median time from date of HIV test to receipt of report by the state health department was 20 days (range: 1–847 days). During October–November 1997, all 72 providers in nine counties of eastern Maryland (the counties reported 3% of AIDS cases in Maryland in 1996) for whom laboratories had submitted HIV-infection reports were contacted to determine the proportion of providers who maintain the required surveillance log linking UI to patient identifiers; 32 (44%) of these providers maintained logs.

Completeness of HIV-infection reporting was estimated by comparison to cases of AIDS reported in the AIDS surveillance registry. Of AIDS cases with dates of HIV diagnosis from July 1995 through June 1996, data elements to construct UI were available for 633 (85%) cases. Of these, 319 (50%) matched to HIV-infection reports with full UI in the UI database (Table 2).

Data from the Maryland HIV counseling and testing (C&T) system (excluding sites offering only anonymous HIV tests) were used to evaluate the proportion of records

[1] HIV-infected persons with a CD4+ T-lymphocyte count of <200 cells/μL meet the 1993 expanded AIDS surveillance case definition and are reportable by name for AIDS surveillance.

HIV Case Surveillance — Continued

TABLE 1. Number of reports of HIV infection and percentage of reports that included data elements for unique identifiers (UIs), by reporting period — Maryland (MD) and Texas (TX), July 1994–December 1996

Reports/Data element	State	July–Dec. 1994	Jan.–June 1995	July–Dec. 1995	Jan.–June 1996	July–Dec. 1996	Overall
Total no. reports	MD	2,238	1,691	1,866	1,881	2,295	9,971
	TX*	3,932	3,399	3,597	2,852	2,339	16,119
Data element†							
Social Security number	MD	69.6	73.1	81.2	83.5	84.5	78.4
	TX	56.7	68.6	65.0	69.5	75.2	66.0
Date of birth	MD	95.2	96.3	98.7	99.3	98.8	97.6
	TX	88.4	89.8	93.1	96.8	97.6	92.6
Sex	MD	96.8	97.2	98.7	99.2	99.4	98.3
	TX	91.5	97.5	98.4	99.1	97.9	96.6
Race/Ethnicity	MD	85.8	88.5	91.8	94.0	89.9	89.8
	TX	80.8	91.6	94.4	97.1	95.4	91.1
% Reports with full UI	MD	61.3	65.9	74.9	78.5	76.5	71.4
	TX	51.8	61.9	61.6	66.5	71.3	61.6

*Excludes approximately 7000 records that had three or more missing UI data elements.
†Proportion of all reports containing specific UI data elements.

with full UI and completeness of HIV-infection reporting. In early 1995, counselors were instructed to obtain UI code information from clients and record the UI on the HIV C&T record. During 1995–1996, a total of 1093 records with a positive HIV test were entered into the C&T database; of these, all UI elements were present for 94%. HIV C&T reports for persons who had HIV diagnosed from July 1995 through June 1996 were matched to the UI database. Of the 528 reports, 276 (52%) matched.

Texas

In 1994, the Texas Board of Health amended regulations to require named reporting of HIV-infected children aged <13 years and UI reporting of HIV-infected adolescents and adults. Both health-care providers ordering an HIV test and laboratories performing the test report confirmed HIV infections to the Texas Department of Health (TDH) through the local health departments. Neither providers nor laboratories are required to maintain registries linking UI to patient identifiers.

Approximately 23,000 HIV-infection reports were received at TDH during the evaluation period. Since 1995, TDH excluded approximately 7000 paper HIV reports with three or more missing UI data elements. Of 16,119 HIV-infection reports entered into the UI database, all UI elements were present for 9923 (62%) (Table 1). Element-specific presence ranged from 66% (SSN) to 97% (sex). Overall, 60% of reports were submitted in periodic batches, which had a longer time from date of HIV test to receipt by TDH (median: 173 days; range: 26–974 days) than the 40% of reports submitted individually (median: 59 days; range: 2–906 days).

Completeness of HIV-infection reporting was estimated by comparison to AIDS surveillance data using the same methodology as in Maryland. Data elements to construct UI were available for 1762 (79%) of AIDS cases with dates of HIV diagnosis in the

HIV Case Surveillance — Continued

TABLE 2. Percentage completeness of HIV-infection reporting, availability of unique identifier (UI) data elements in alternate databases, and sources of report — Maryland and Texas, July 1994–December 1996

Characteristic	Maryland (n=9,971)	Texas (n=16,119)
Completeness of reporting		
HIV*	50.4	26.0
CD4+ T-lymphocyte count*	44.4	NA†
HIV§	52.3	NA
Availability of UI data elements in alternate databases		
Birth¶	No	No
Death	Yes	Yes
Sexually transmitted disease	No	No
Tuberculosis	No	No
Drug assistance**	Yes	Yes
Medical assistance††	Yes	No
Hospital discharge	No	No
Source of HIV report		
Public	30%§§	77%§§
Private	70%¶¶	23%***

*AIDS cases reported through July 1997 compared with the UI database.
†Not available.
§HIV cases diagnosed from July 1995 through June 1996 in HIV counseling and testing sites compared with the UI database.
¶Used for pediatric AIDS surveillance only.
**Federal- and state-funded medication program.
††Federal- and state-funded medical-assistance program.
§§Includes local health departments and state laboratory.
¶¶Includes community-based organizations and private clinics and laboratories.
***Includes community-based organizations, hospitals, private physicians, clinics, and laboratories.

specified period (Table 2). Of these, 454 (26%) matched to HIV-infection reports with full UI in the UI database.

To evaluate the feasibility of epidemiologic follow up, TDH sampled 765 HIV-infection reports submitted during January 1995–June 1996, in six areas of the state, reflective of variation in geography, demography, HIV morbidity, and reporting sources. Of these, 456 (60%) could be matched to a client record using any combination of UI (including records without full UI), health-care provider name, date of test, residential information, and other locally available information. Matched records that were missing the SSN data element (n=208) were reviewed to determine whether these data could be located. SSN could not be located for 120 (58%) of these records.

Reported by: L Solomon, DrPH, L Eldred, DrPH, J Markowitz, PhD, P Ryan, MS, G Benjamin, MD, Maryland Dept of Health and Mental Hygiene. AS Robbins, PhD, CW Hamaker, SA King, MA, SK Melville, MD, MC Thomas, MS, DM Simpson, MD, State Epidemiologist, Texas Dept of Health. Div of HIV/AIDS Prevention–Surveillance and Epidemiology, National Center for HIV, STD, and TB Prevention, CDC.

HIV Case Surveillance — Continued

Editorial Note: HIV and AIDS surveillance data are needed to provide reliable population-based data to guide public health programs. During 1995–1996, the first declines in the incidence of AIDS-opportunistic infections and AIDS deaths were reported in the United States (6% and 23%, respectively), in part, as a result of increasingly effective HIV therapy (*1*). On the basis of revised HIV treatment guidelines (*2*), the impact of treatment advances on AIDS trends is expected to continue and will reduce the usefulness of AIDS data alone to monitor HIV-infection trends and morbidity. CDC and other public health and advocacy organizations have recognized the need for national HIV case surveillance while continuing to discuss the relative merits of HIV surveillance methods based on numeric codes compared to the name-based approach employed for AIDS surveillance (*1,3*).

CDC uses established criteria to evaluate performance of public health surveillance systems to provide accurate data to target prevention and care programs (*4*). States conduct active surveillance using existing name-based clinical and public health records to decrease the reporting burden on providers, eliminate duplicate reports, and facilitate epidemiologic follow-up. These methods enable AIDS surveillance to attain high performance standards as reflected by completeness of reporting (>85%) (*5*) and documentation of risk exposures (≥93% of cases) (*6*). Evaluation of name-based HIV surveillance has shown 74%–97% completeness of reporting (*7*; CDC, unpublished data, 1997), and documentation of risk exposures (≥76% of cases) (*6*). Secure and confidential surveillance practices are required as a condition for receipt of federal resources for HIV and AIDS surveillance. At the state level, the most comprehensive protections of medical data apply to government-held data, and most specifically to HIV-related data (*8*). Names are removed before encoded and encrypted AIDS or HIV surveillance data are transmitted to CDC.

The evaluations in Maryland and Texas indicated that the use of UIs limits the performance of an HIV surveillance system and complicates efforts to collect risk-behavior information. Both systems demonstrated timely reporting. Although data from both states indicated increases in reporting of the SSN data element during the evaluation period, overall 22% of reports in Maryland and 34% in Texas were missing the SSN element, which contributed to a high rate of incomplete case reporting. The follow-back investigation in Texas suggests that SSNs are not readily available in client or medical records but, in the controlled environment of the Maryland HIV C&T system, counselors were able to collect SSNs for most clients. The completeness of reporting also may be affected by the ability of providers and laboratories to use UIs as part of routine HIV-testing practices. For example, one large laboratory providing HIV-testing services in Maryland did not report HIV infections during the evaluation period. The difficulty in collecting HIV data when persons are tested out of state also may affect completeness of reporting and the ability to eliminate duplicate reports. Maryland is continuing to evaluate its UI surveillance system, and Texas is exploring alternative HIV surveillance systems with input from community groups.

Effective HIV surveillance systems must include HIV risk information; however, this information often is not available at the time of the initial UI case report, and follow-up with health-care providers is necessary. To supply follow-up information, health-care providers must use lists or other mechanisms to link the UI to patient identifiers. The UI approach complicates efforts to collect this information and increases the number of lists of HIV-infected persons that could be disclosed in a breach of confidentiality.

(Continued on page 1271)

HIV Case Surveillance — Continued

CDC has recommended that all states and territories conduct HIV case surveillance as an extension of their AIDS surveillance systems (*1*). In addition, CDC is developing technical guidance to enhance security practices, standardize confidentiality laws and regulations, and promote uniform standards for HIV case surveillance systems. These guidelines will assist states and territories in implementing HIV case surveillance using data-collection and data-storage methods that provide high quality HIV surveillance data while assuring the confidentiality of surveillance information.

References

1. CDC. Update: trends in AIDS incidence, 1996. MMWR 1997;46:861–7.
2. Carpenter CC, Fischl MA, Hammer SM, et al. Antiretroviral therapy for HIV infection in 1997: updated recommendations of the International AIDS Society-USA panel. JAMA 1997;277:1962–9.
3. Council of State and Territorial Epidemiologists. CSTE: position statement ID-4. National HIV surveillance: addition to the National Public Health Surveillance System. Atlanta, Georgia: Council of State and Territorial Epidemiologists, 1997.
4. Klaucke DN. Evaluating public health surveillance. In: Teutsch SM, Churchill RE, eds. Principals and practices of public health surveillance. New York, New York: Oxford University Press, 1994:158–74.
5. Rosenblum L, Buehler JW, Morgan ME, et al. The completeness of AIDS case reporting, 1988: a multisite collaborative surveillance project. Am J Public Health 1992;82:1495–9.
6. CDC. HIV/AIDS surveillance report. Atlanta, Georgia: US Department of Health and Human Services, Public Health Service, 1997. (Vol 8, no. 1).
7. Meyer PA, Jones JL, Garrison CZ. Completeness of reporting of diagnosed HIV-infected hospital inpatients. J AIDS 1994;7:1067–73.
8. Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996:275:1921–7.

Contributors to the Production of the *MMWR* (Weekly)

Weekly Notifiable Disease Morbidity Data and 122 Cities Mortality Data

Denise Koo, M.D., M.P.H.

State Support Team
Robert Fagan
Karl A. Brendel
Siobhan Gilchrist, M.P.H.
Harry Holden
Gerald Jones
Felicia Perry
Carol A. Worsham

CDC Operations Team
Carol M. Knowles
Deborah A. Adams
Willie J. Anderson
Christine R. Burgess
Patsy A. Hall
Myra A. Montalbano
Angela Trosclair, M.S.

Desktop Publishing and Graphics Support
Morie M. Higgins
Peter M. Jenkins

NY Times

U.S. Urges Reporting of H.I.V. Patients

A Step That Many States Have Avoided, Amid Questions of Privacy

By LYNDA RICHARDSON

In deliberate but cautious steps, the Centers for Disease Control and Prevention is urging states to require that people infected with H.I.V. be reported to state health departments, following the same practice used for infectious diseases like tuberculosis and syphilis.

AIDS cases are required to be reported in every state. But officials in New York and many other states have refrained from similar reporting efforts with H.I.V.-positive patients who do not have the symptoms that meet the definition of AIDS. Many groups of advocates for people with AIDS have said that reporting H.I.V. patients would deter people from getting tested and receiving early treatment.

Twenty-six states, including New Jersey, now have H.I.V. reporting. Those states, however, account for just 24 percent of all AIDS cases reported through last year. New York, which had the highest rate of reported AIDS cases last year, does not require H.I.V. reporting.

In an article published Thursday in The New England Journal of Medicine, Dr. John W. Ward, the chief of the centers' H.I.V.-AIDS surveillance branch, and two co-authors propose a national system of mandatory H.I.V. reporting. The authors argue that better drugs have delayed the progression to AIDS-related illnesses and death for many people, and that AIDS no longer lends itself to monitoring based only on its most advanced stage.

"Unless we revise our surveillance system," the authors wrote, "health authorities will not have reliable information about the prevalence, incidence, and future directions of H.I.V. infection, the kinds of behavior that currently increase the risk of H.I.V. transmission, or the heightened impact on specific subpopulations, such as racial and ethnic minorities and women. To correct these deficits, we propose all states require H.I.V. case reporting."

In the last few months, public discussions have intensified over H.I.V. reporting, as the C.D.C. has convened two meetings with state and Federal health experts and the leaders of prominent advocacy groups for AIDS patients. And on Sept. 19, in one obscure sentence of a weekly morbidity and mortality report published by the centers, the agency made its first official statement that H.I.V. reporting should be conducted nationwide.

Early next year, the health agency plans to issue a set of recommendations that will address whether the names of H.I.V.-positive people should be reported to health departments, a practice that is opposed by many advocacy groups that favor coded identification.

The journal article was written by Dr. Ward of the Atlanta-based centers; Lawrence O. Gostin, a director of the Georgetown University-Johns Hopkins University Program on Law and Public Health and a member of the health agency's advisory committee; and A. Cornelius Baker, the executive director of the National Association for People With AIDS, a leading constituency group based in Washington.

Many advocacy groups have softened their opposition to H.I.V. reporting in recent months because of medical advances, but most groups, including the one headed by Mr. Baker, have resisted revealing names. Last month, the National Association for People With AIDS adopted a policy that such reporting should be supported "under no circumstances." Mr. Baker characterized the journal article as neutral on whether to use names or coded identification.

Seeking to treat H.I.V. infection like other diseases.

But the article said coded identification did not provide reliable data at a reasonable cost, citing two states, Maryland and Texas, that use coded identifiers that consist of the last four digits of the Social Security number, as well as birth date, sex and race.

In addition, the authors wrote that H.I.V. reporting would not create unique privacy concerns. The names of infected people already have been entered into other data bases, like those of Medicaid and drug-assistance registries, in addition to being widely used by insurers, managed-care organizations and researchers, the authors said.

A national system of H.I.V. reporting by name would remove a cloak of privacy that has long surrounded AIDS. The move would greatly expand, by tens of thousands, the number of infected people listed in Government records and would generate a firestorm of debate over potential invasions of privacy and discrimination.

Some states, including New York, would require legislation to conduct H.I.V. reporting, though many other states could put it into effect through health department regulations.

To counter the journal article, the American Civil Liberties Union issued a position paper last week on H.I.V. reporting, its first in nearly a decade. It said reporting names was "bad public policy," and cited numerous studies that indicate it would drive infected people underground.

Michael Adams, a staff counsel with the American Civil Liberties Union's AIDS Project, said in an interview that his organization was not opposed to H.I.V. reporting as long as coded identification was used. But Mr. Adams said the tone of the journal article "seems to focus on the weaknesses of unique identifiers without focusing on the weaknesses of name reporting."

"It's no secret that this is a step that the C.D.C. is seriously talking about taking," Mr. Adams said. "We hope we can jump into the debate and influence where they are going with this."

The Centers for Disease Control cannot force states and cities to comply with its recommendations because it is not a regulatory agency. But the agency, which sends Federal money to health departments for surveillance purposes, has the power to condition the terms under which they receive the funds, Mr. Gostin said. The centers could effectively force the states and the six cities hard hit by the epidemic to comply by changing the terms of their cooperative agreements, Mr. Gostin said.

In New York City, which has the largest number of AIDS cases in the nation and receives agency funds independently from the state, 88 percent of a $4.2 million AIDS surveillance budget comes from the Federal agency.

Dr. Ward of the centers said in an interview that there were no "immediate plans" to link Federal funding to a willingness to conduct mandatory H.I.V. reporting.

But Dr. Ward did not rule out a change of the terms under which states and cities receive Federal surveillance funds. "That's something we have to decide on," he said.

Vancouver, a City With Everything, Finds It Has AIDS Too

VANCOUVER, British Columbia, Oct. 20 (AP) — In this modern, up-to-date city, a pocket of poverty is reeling from one of the worst AIDS epidemics in any wealthy nation.

Fifteen blocks known as Downtown Eastside form the poorest urban neighborhood in Canada — a seamy mix of pawn shops, taverns and decrepit rooming houses. The Eastside's drug addicts are becoming infected with H.I.V., the virus that causes AIDS, at such a rapid pace that health officials have declared the first medical emergency ever in Vancouver.

Experts estimate more than 6,000 addicts frequent the area, perhaps half of them infected with the virus because of pervasive sharing of contaminated needles.

Dr. Martin Schechter, an epidemiologist at the University of British Columbia, said the infection rate among Eastside drug users is nearly 20 percent annually.

The problem has been building for several years, but came into the spotlight this month when Bud Osborne, a community leader and former addict, convinced fellow members of Vancouver's health board to declare a medical emergency. "This epidemic is kind of like the plague," Mr. Osborne said in an interview. "It's going to spread."

Under the emergency, the province allocated $2.2 million to combat the epidemic, and pressure is rising for the national Government to help.

The epidemic is raging despite the city's ambitious needle-exchange program, which started in 1988. More than 2.5 million clean needles are distributed annually, but many addicts do not bother to use them.

Dr. Schechter said H.I.V. infections in the Eastside began multiplying about four years ago when many addicts changed habits: they switched to a dozen or more injections a day of cheap cocaine, rather than two or three of heroin.

"The number of injections per day goes up — the ability to take precautions goes way down," he said.

Though other Canadian cities have similar problems among drug-users, the Eastside stands out in an otherwise prosperous city that is assuming an international role.

Some of Vancouver's addicts are Indians from impoverished rural reservations, but the city's mild winters and relatively generous social programs also attract the down-and-out from across Canada.

"These are people who are totally marginalized, and there's a very callous attitude toward them," said Libby Davies, who was elected this year to Parliament from the district that includes the Eastside.

Ms. Davies has been frustrated by the reaction to her pleas for assistance: She said the Health Minister told her it was a problem for the Justice Ministry, and the Justice Minister told her it was a health problem.

Precise statistics are hard to come by, but the Vancouver Native Health Society earlier this year registered 600 drug-addicted Indians in the Eastside who were H.I.V.-positive. The society says that at least 31 have died, and that it is recording a new infection each day.

The health board has asked its staff to develop a plan of action by the end of this month. This will probably include expanded needle-exchange and addiction treatment, and recommendations to improve living conditions in the Eastside.

Real estate prices in Vancouver are among the highest in Canada, and little low-income housing is being built. Mr. Osborne, the community leader, said owners of the Eastside's cheap hotels are content to let them deteriorate, hoping the area will turn around, lifting property values.

Richard Cohen

Washington Post
10/21/97
A19

Gays: The Attitude of '63

In "Gay Metropolis: New York City 1940-1996," Charles Kaiser writes of the time when a New York Times editor, noticing more and more gays in Gotham, ordered up a story that referred to homosexuals in the alarmed manner medieval Europeans must have used when talking about the Black Death. "Growth of Homosexuality in City Provokes Wide Concern," said the Page 1 headline. The year was 1963, yet somehow, the United States went on to win the Cold War.

The stunning homophobia of that article, routine for the times, if not the Times, seems almost incomprehensible now. And yet, it was only in 1993 that a distinguished senator, alarmed that President Clinton might allow gays into the armed services, rushed down to some military base to measure the distance between bunks. This was Sam Nunn of Georgia, a usually sagacious man who let his prejudice and ignorance get the better of him.

In the end, Clinton had to swallow a measly compromise with both the Nunns of the Senate and the Colin Powells of the military and settle for his "Don't Ask, Don't Tell" policy, which still treats gays as pariahs. In fact, some gay and lesbian organizations insist things are worse for homosexuals in the military now than it was before Clinton attempted reform.

So it is meaningful that Vice President Al Gore last week chose to praise the television show "Ellen," whose main character came out of the closet last season—as did Ellen DeGeneres, the actor who plays Ellen. The upshot (if you happened to be on the Mir space station at the time) was the usual Time-Newsweek-People tsunami of publicity and the solemn assurance that nothing will ever be the same—until next week, that is.

Still, these things do have an effect. It is not the effect some people seem to fear—that heterosexuals will become homosexuals in numbers that once so worried the New York Times. It is, instead, that people will see that Ellen the perceived heterosexual was not all that different from Ellen the announced homosexual. Viewers "were forced," as Gore inelegantly put it, "to look at sexual orientation in a more open light."

Now this is subversive stuff, the Kryptonite of bigotry. For once you recognize that the object of your loathing is pretty much like you, hate becomes difficult. If, for instance, you understand that gays have been in the military since there have been gays and militaries—way before Sam Nunn, that is to say—then you might understand that the best policy is virtually no policy whatsoever. Why can't a person be what he or she is—as long as he doesn't bother other people? This is the policy, I take it, when it comes to heterosexuals.

It goes almost without saying that Gore's sensible remarks were instantly denounced by conservative groups and, of course, Dan Quayle. The former vice president had this to say: "I'm always surprised to hear politicians promoting the agenda of Hollywood elites. If there's anybody whose agenda needs promoting, it is the middle-class American family."

I am confused. What gives Quayle the idea that middle-class people cannot be homosexual? In fact, it is these people—and not the sons and daughters of the elite—who run into trouble in the military and are most dependent on the tolerance of others to keep a job or a place to live. If there is a link between sexual preference and gold card status, science has somehow missed it.

Quayle, it turns out, is a constant. He is immune to intellectual growth—and he is a shameless opportunist. He courts the know-nothing right wing in the event he decides to make a presidential race. But how much more bold it would have been if ol' blue eyes had denounced homophobia as one the few remaining acceptable American prejudices and asked his fellow conservatives to show some tolerance. For one thing, they ought to stop insisting homosexuality is a casual choice. It is, I take it, about as optional as left-handedness.

It is true that Quayle and Gore have different constituencies—and that gay groups play an increasingly important role for Democratic politicians. But it is also true that down the road Gore will be asked to account for his remarks—just as Clinton was made to account for his wooing of the gay vote in 1992. When that time comes—and the Quayles in the GOP will make sure it will—Gore might want to get that 1963 story. Both the Times and much of the nation have moved on. To some on the political right, though, gay bashing will always be news.

Comment
ON THE NATION

TV-H Label: Hazardous to Your Hypocrisy

A warning label on 'Ellen,' where the sexuality is reticent, is insulting.

By Robert Dawidoff

The one surprise about ABC's pinning of a false and misleading child warning label on the hit comedy "Ellen" is the possibility, against all evidence, that the network poobahs have imagination. It takes imagination to preface this season's episodes of Ellen DeGeneres' Emmy winning show with a warning: "due to adult content, parental discretion is advised."

In a world where words still meant what they mean, of course, this would be correct, because adult content—if adult means mature, human, funny, heartwarming, professional, innovative and real—is what distinguishes "Ellen." But of course that isn't what "adult" means on TV.

Of course, everybody know what's up. Last season, the character Ellen Morgan "came out" as a lesbian. And this season's shows have made affecting and brilliant comedy of the consequences.

The concerns that last season's hoopla would result in a preachy, unfunny show have vanished. Millions are laughing along with Ellen and her friends, because her own truth has made her funnier and connected her to shared experience.

"Ellen" is a situation comedy, like "The Mary Tyler Moore Show," "Taxi," "Cheers" and "Roseanne." These shows sharpen the interactions of real people in plausible situations into comedy. We are learning along with the unpredictable Ellen about what it means to be a lesbian and what a funny, bewildering experience that can be.

What is so marvelous about Ellen is how she keeps having to confront her own internalized version of society's narrow mindedness. You don't have to be a lesbian to identify with her, although you may risk having to transcend being scared or intolerant of a different sexual orientation.

show that is sexually reticent and tender. The shows that require no cautions are routinely lewd, vulgar, blatantly and exploitatively sexual as well as pointless.

What is so offensive about the transparent attempts to censor DeGeneres is not only their hypocrisy and craven submission to imagined threats to the profits of the network's owners. What really stinks is what the network is advising parents. ABC is censoring the rare show that is sexually reticent and tender. The shows that require no cautions are routinely lewd, vulgar, blatantly and exploitatively sexual as well as pointless.

Do you want your children to learn about their desires and about love by watching babes and dudes? Shouldn't we be worrying about what it does to people to be told one thing in church or at home about morality and responsibility, while their bodies and fantasies are being manipulated by for profit sexual pandering and merchandizing?

Unlike even the most agreeable gay characters on the tube, Ellen can't be reduced to her sexuality. Part of what makes the show so good is the show has not tried to make Ellen a lesbian who doesn't want love and sex, but has created a character who replaces an oppressive stereotype by being, like all great comedians, an extraordinary ordinary human being.

The ABCensors apparently don't watch their own shows. "All My Children" has been featuring a story line about Kevin, a young man who has to deal with being gay and encounters the hostility of his family and the kinds of quacks who still claim they can "cure" homosexuality. Last time I tuned in, Kevin had found some support from his would-be girlfriend and some sympathetic adults. As I was watching, however, I was terrified that he would end up being another one of those statistics, gay young people who still kill and hurt themselves because the desires that are natural to them are called unnatural by others.

That is the kind of truth that kills. "Ellen" is the kind that heals.

Maybe ABC should warn parents this way: "Caution, don't let your kids watch this show, it might prove hazardous to your hypocrisy."

Robert Dawidoff is a professor of history at Claremont Graduate School and coauthor, with Michael Nava, of "Created Equal: Why Gay Rights Matter to America."

... WALL STREET JOURNAL 10/21/97 B19

Panel's Prescription for Quality Care Will Be Core of Health-System Overhaul

By LAURIE MCGINLEY
Staff Reporter of THE WALL STREET JOURNAL

WASHINGTON – President Clinton is poised to endorse a broad range of patient protections being developed by an advisory panel charged with improving the quality of managed health care, administration officials said.

Beefed-up consumer guarantees are the next logical move in the president's step-by-step effort to alter the nation's health-care system, aides said. The panel's recommendations will become the core of a legislative proposal that will be one of the administration's top priorities next year.

Dubbed the "Consumer's Bill of Rights," the recommendations are being hammered out by a subcommittee of the president's advisory panel on consumer protections and quality in the health-care industry. The full 34-member commission, which was appointed in March, is scheduled to debate the recommendations today and may adopt them as early as tomorrow.

But some consumer representatives, however, worry that the proposed protections might not go far enough and changes still may occur. Ron Pollack, a member of the subcommittee and executive director of Families USA, a health-policy group, said that he will continue to press for more sweeping protections. He contended that while the proposed changes would be a step forward, they are far too limited. "It's like having the true Bill of Rights without the freedoms of speech or religion," he said. "The rest of the rights may be worth adopting, but the document still falls short overall."

Administration officials said they expect the consumer groups to line up behind the consumer package because it would be a major improvement over the status quo. In particular, consumer groups are enthusiastic about a provision that, under certain circumstances, would guarantee patients the right to appeal denial of care decisions to an unbiased third party for a binding ruling.

The proposal also says that consumers have the rights to accurate, easily understood information about their health plans; a wide enough choice of health-care providers to assure good care "without unreasonable delay"; to confidentiality for their medical records, and to be reimbursed for emergency-medical care in a situation that a "prudent lay person" would judge to be an emergency, even if it turned out not to be. The report's preamble says it's "intolerable" that 41 million Americans don't have health insurance.

But the subcommittee hasn't reached consensus on several other issues being pushed by consumer groups, including requiring ombudsman programs to help consumers navigate choices offered by health plans; eliminating or raising the caps on health-insurance coverage, and ending the unequal treatment by insurers of physical and mental ailments. The commission is expected to begin debate today on whether any of these ideas should be added. Business and managed-care plans have argued that some of these proposals would drastically drive up costs and may result in companies dropping coverage entirely.

The commission is expected to send its bill-of-rights report to President Clinton by Thanksgiving, and then to focus on its next job – writing a report, due in March, on how to create a framework for improving health-care quality. The panel's members include consumer, labor and business representatives, health insurers and providers, quality experts and state and local government officials.

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

EXECUTIVE SUMMARY OF THE HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION

Changes in the epidemic have led many public health officials to express increasing concern that existing AIDS surveillance efforts are becoming outdated. This has often resulted in the call for some type of HIV reporting system.

The San Francisco AIDS Foundation acknowledges there is a need for improved HIV data, if this information is used appropriately to better plan for future service needs, target and evaluate prevention efforts, and inform resource allocation decisions. **However, we strongly disagree that HIV *names* reporting is necessary to accomplish these goals, and we do not believe that the benefits of names reporting outweigh the potential negative repercussions associated with this type of surveillance system (such as the possibility that some individuals would be deterred from seeking HIV testing and/or treatment under such a system).**

Any system that is developed should meet the goals of HIV surveillance and the criteria by which HIV surveillance systems should be evaluated that are outlined below. Non-names based surveillance systems that may be able to meet these goals and criteria, such as reporting systems that utilize unique identifiers, must be more aggressively examined in an unbiased fashion as a viable alternative to HIV names reporting.

Goals and Appropriate Uses of HIV Surveillance Data

We believe that HIV surveillance should only be designed to help meet the following goals:

- Better determine and understand the demographic and risk profiles of the current epidemic;
- Plan for future health care and social service needs;
- Track new incidence of HIV in order to target prevention efforts;
- Evaluate overall efficacy of prevention efforts;
- Inform rational resource allocation.

Any HIV surveillance system that is developed should include specific mechanisms to ensure that surveillance data is utilized to meet these goals. In addition, although certain activities are worthy goals of HIV testing and treatment programs—such as linking individuals to care and treatment or identifying additional individuals who have possibly been exposed to HIV—these are not appropriate uses of HIV surveillance data. HIV reporting will not make treatment more available or accessible and is not needed to conduct effective partner notification.

Criteria That Should Be Utilized to Evaluate HIV Surveillance Efforts

The Foundation believes there are reasonable and appropriate criteria that must be met to justify the use of any particular HIV surveillance system. Specifically, an HIV surveillance system should:

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901

- Not create a disincentive to testing and/or treatment;
- Produce information that is actually utilized for planning and evaluation purposes in a manner that has the potential to improve the community's health;
- Not violate confidentiality and/or civil rights and should include strong enforcement and penalties for disclosure of information;
- Not come at the expense of resources for treatment/services;
- Respect individual choice with respect to name disclosure.

Only by meeting these criteria will a system provide sufficient benefit to outweigh any potential negative or damaging consequences. A mandatory name-based reporting system would run counter to several of these criteria and should under no circumstances be required or encouraged. Other systems that do not rely on names, such as some type of unique identifier system, should be pursued if it is determined that such a system also meets these criteria.

Unique Identifier Reporting Must Be Examined as a Viable Alternative

The primary HIV surveillance system that is considered a potential alternative to names reporting is unique identifier reporting. Under such a system, an HIV-infected individual would not be reported by name to public health officials, but rather by some form of a unique code that could not be traced back to the person. Many have argued that the data regarding the effectiveness of unique identifier systems show that these systems are inadequate and that names reporting is the only viable HIV surveillance system available. The Foundation disagrees with this conclusion. We do not believe that unique identifier reporting systems have been judged fairly in the national debate regarding HIV surveillance systems. Specifically:

- Unique identifier systems have not been funded adequately.
- The evaluation of the current unique identifier systems has not taken into account the fact that these systems are relatively new.
- The standard used to judge unique identifier systems has been set unnecessarily high. Absolutely complete and accurate data is not needed to analyze broad trends in the epidemic.
- The fact that many states have implemented names-based reporting does not provide a legitimate rationale for opposing unique identifier reporting (in fact, approximately 75% of individuals living with HIV reside in states that do not report HIV cases by name).

The Foundation believes that if public health officials commit to providing proper attention and time to developing such a system, a reporting mechanism could be developed that would provide adequate and necessary surveillance data while greatly reducing the public health and privacy concerns related to name based reporting.

In conclusion, the Foundation agrees that improved HIV surveillance data, if used appropriately, could benefit people living with HIV. However, collection of this data must be done in a manner that minimizes the potential for harm to these same individuals. We will continue to work to establish a system that meets both of these important goals.

For a copy of the complete, seven-page position statement, please contact the San Francisco AIDS Foundation Public Policy Department at (415) 487-3080.

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION

Introduction

Changes in the epidemic have led many public health officials to express increasing concern that existing AIDS surveillance efforts are becoming outdated. Because new treatment options are thankfully slowing or stopping disease progression in many individuals living with HIV, greater numbers of individuals are not progressing to AIDS. These individuals are therefore not being reported systematically to public health entities (since in California and many other states, only AIDS cases are reportable). As a result, some public health officials have argued that AIDS case data are becoming less indicative of both the number and the demographics of individuals who are actually HIV-infected. Often, this has led to the call for HIV names reporting, whereby all individuals living with HIV would be reported by name and other identifying information to their local and/or state health departments.

The San Francisco AIDS Foundation acknowledges there is a need for improved HIV data, if this information is used appropriately to better plan for future service needs, target and evaluate prevention efforts, and inform resource allocation decisions. **However, we strongly disagree that HIV *names* reporting is necessary to accomplish these goals, and we do not believe that the benefits of names reporting for people living with HIV outweigh the potential negative repercussions associated with this type of surveillance system (such as the possibility that some individuals would be deterred from seeking HIV testing and/or treatment under such a system).**

Although the Foundation remains strongly opposed to mandatory names reporting, other HIV surveillance and/or reporting systems may be available or developed that could provide better data regarding the HIV epidemic without having the potentially negative impact of names reporting. This could include some type of HIV reporting by unique identifiers, in which an individual is assigned a unique and confidential code that is reported, expanded use of seroprevalence and seroincidence studies, or some other type of surveillance mechanism.

The remainder of this document outlines what we believe are the goals and appropriate uses of HIV surveillance systems, as well as criteria that should be used to judge any HIV surveillance system that is implemented. Non-names based surveillance systems that may be able to meet these goals and criteria, such as reporting systems that utilize unique identifiers, must be more aggressively examined in an unbiased fashion as a viable alternative to HIV names reporting.

Goals and Appropriate Uses of HIV Surveillance

We believe that HIV surveillance should only be designed to help meet the following goals:

- **Better determine and understand the demographic and risk profiles of the current epidemic.** Relying exclusively or primarily on AIDS reporting and surveillance makes it difficult to obtain a current "snapshot" of the HIV epidemic, and this is becoming even more problematic as fewer individuals are progressing to AIDS. However, it should be noted that HIV reporting data would be limited in that it would only provide information on those who self-select to be tested at a site where they are reported to government officials and/or those who seek health care for their HIV status. This data would in no way provide comprehensive information on all individuals who are HIV-infected.

- **Plan for future service needs.** The data gathered through HIV surveillance have the potential to provide community planners, leaders, and advocates with information to better assess and plan for upcoming healthcare and support service needs for people living with HIV/AIDS.

- **Track new incidence of HIV in order to target prevention efforts.** Ideally, HIV surveillance data could help us to better identify who is currently becoming infected (i.e. which risk behaviors and/or populations) and identify new trends in the epidemic, so that prevention efforts could be more quickly directed to those individuals at greatest risk for infection.

- **Evaluate overall efficacy of prevention efforts.** Surveillance information could also be used to help in broadly assessing the effectiveness of HIV prevention strategies. If HIV surveillance demonstrates that HIV infections are continuing to increase in a community, this may indicate a need to re-evaluate, alter and/or expand prevention efforts.

- **Inform rational resource allocation.** This data and its ability to assist in planning for future needs and targeting and evaluating prevention efforts could also be used to better inform resource allocation decisions. Surveillance data has the potential to inform both HIV-specific decisions (e.g., to determine funding for different HIV-specific services or for particular HIV-affected populations) and to inform broader, non-HIV specific funding decisions (e.g., determining spending for HIV and/or health care broadly as compared to other services or issues).

Any HIV surveillance system that is developed should include specific mechanisms to ensure that surveillance data are utilized to meet these goals. Far too often, surveillance systems have been developed that do nothing more than collect data, but are never actually used in a meaningful way to plan for improved service delivery or to inform the resource allocation process. It is unacceptable to collect this data without it clearly being used to meet goals that will benefit individuals living with HIV/AIDS. If the data collected through an HIV surveillance and/or reporting system are not actually utilized for these purposes or fail to meet these goals, the

surveillance system should be terminated and any resources being used to implement such a system should be redirected to other urgent health care needs.

In addition, the Foundation believes that the goals listed above are the *only* legitimate and justifiable goals of HIV surveillance. Other ways in which HIV surveillance information could be used have been identified, such as increasing direct access to HIV care and treatment and identifying additional individuals who have possibly been exposed (e.g. partner notification efforts). Although these are worthy goals of HIV testing and treatment programs, the Foundation does not agree that these are appropriate goals for HIV surveillance. Specifically:

- **HIV surveillance and/or reporting will not make treatment more available or accessible.** Instead, adequate funding levels of HIV care and treatment services are needed to expand access to new HIV treatments. San Francisco serves as an exemplary model for getting individuals tested and into early treatment and care not because of any sort of HIV reporting system, but because the City has assured adequate funding for these services. HIV surveillance or reporting will not in any way expand or improve access to care services.

- **HIV reporting is not needed to conduct effective partner notification.** Partner notification programs are already in place throughout California without any type of HIV reporting. If an individual is offered counseling on how to tell his or her previous partners about possible exposure to HIV or given the opportunity to have the local health department notify these partners, there is no need to have the initial case reported to the government. In fact, HIV reporting by name could actually *discourage* partner notification efforts because some individuals might be more reluctant to provide information about their partners if they know that their own name is going to be reported to a governmental entity.

Surveillance and reporting efforts have also been justified or used in extraordinarily inappropriate ways that actually harm or punish people living with HIV/AIDS. Specifically, HIV surveillance or reporting systems must be designed so that they can never be utilized to: (1) quarantine those with HIV; (2) penalize and/or criminalize individuals accused of transmitting or exposing others to HIV; or (3) assist in coercive efforts to mandate use of HIV treatments. In addition, these systems should never be used to create and/or maintain a perception the government is appropriately and adequately responding to the epidemic. HIV surveillance and/or reporting funding should in no way replace current prevention efforts or care and treatment services.

Finally, some have argued that HIV should be reportable in order to ensure that standard public health tools are applied to HIV. The Foundation does not believe that this justification, in and of itself, is a necessary or important goal. Unless applying standard public health tools to HIV actually meets the appropriate goals of HIV surveillance that are identified above, there is not an inherent value to applying these tools. Furthermore, these public health tools have not proven themselves to be unilaterally effective in stemming the spread of other diseases and their usefulness must be evaluated in regards to each particular public health issue. Any system that is implemented should be designed in a way that acknowledges both the strengths and weaknesses of "traditional" surveillance systems and public health methods.

Criteria That Should Be Utilized to Evaluate HIV Surveillance Efforts

As noted above, the Foundation agrees that improved surveillance efforts have the potential to improve HIV prevention efforts as well as care service delivery and planning. However, we also recognize that these same systems can have negative consequences for people living with HIV and those at risk for HIV infection, such as deterring individuals from seeking testing and/or treatment, shifting resources from other HIV services into surveillance, and violating individuals' confidentiality and/or civil rights. It is absolutely critical that we examine the trade-offs between obtaining better data and possible negative impact of this process. Thus, there must be a careful examination of any surveillance or reporting system that is proposed.

The Foundation believes there are reasonable and appropriate criteria that must be met to justify the use of any particular HIV surveillance system. Specifically, an HIV surveillance system should:

- **Not create a disincentive to testing and/or treatment.** Several studies have shown that some HIV reporting systems (in particular, names reporting) may reduce people's willingness to get tested. Given that an estimated one-third of those believed to be HIV-infected have never been tested, surveillance systems should not in any way discourage individuals at high risk for HIV infection from being tested. Specifically, anonymous testing must remain accessible and available to anyone who would prefer this testing option. Anonymous testing must be accessible geographically (i.e., individuals should not have to travel great distances to obtain anonymous testing), at convenient hours (including times in which individuals are not working), and should be provided free of any charges or fees.

  However, the availability of anonymous testing is not sufficient to address these concerns. Some individuals might get tested anonymously, find out that that they were HIV infected and then avoid treatment because of fear of being reported to the government when accessing the health care setting. In light of the treatment options that now exist, it is more important than ever that individuals be encouraged to seek HIV testing and early treatment. Any HIV surveillance system that is developed must also minimize individuals' concerns so that they are not discouraged from seeking early care and treatment. Mandated reporting by name would be the most likely system to increase individuals' reluctance to seek treatment.

- **Produce information that is actually utilized for planning and evaluation purposes in a manner that has the potential to improve the community's health.** As discussed in the goals section, it is absolutely critical that this surveillance data actually serve an important public health role in providing useful and timely information that is used to inform community planning and target and evaluate prevention efforts. If a surveillance system does not prove to be useful in this regard after its implementation, this data collection exercise should be stopped. Specifically, this data should clearly provide individuals living with HIV and those at risk for HIV infection with meaningful information to make decisions for themselves and should be used to ensure adequate availability of care and treatment services for people living with HIV.

In addition, surveillance data should provide useful and timely information that is accessible to the community (i.e., the data should be shared and widely distributed within the community). If the data is not timely or accessible, it will not provide sufficient benefit to people living with HIV to justify such a system.

It should also be noted that such data does not have to be 100% accurate and complete to provide useful information in discerning trends in the epidemic and planning for future service needs. Even with the most accurate data on AIDS cases, there is often a significant time lag between the AIDS diagnosis and the report to public health officials. Incomplete or imperfect data will certainly provide more information than we now have available, which would greatly help in determining broad trends in the epidemic. Accurate trend data is the most important information needed in order to conduct thoughtful planning.

- **Not violate confidentiality and/or civil rights and should include strong enforcement and penalties for disclosure of information.** Surveillance systems have the potential to be used for inappropriate purposes, such as utilizing lists to demonstrate knowledge of HIV status when attempts are made to punish individuals accused of exposing others to HIV infection. Although health departments have generally been extremely careful with this type of information, these departments could be compelled by legislative mandate or judicial order to surrender HIV case reports. For example, a recent United States Department of Health and Human Services proposal could lead to expanded law enforcement access to medical records. It is possible that this could include public health records, such as HIV case reports. In addition, although breaches by public health officials have been rare, they have occurred (most dramatically in Florida in 1996), and greatly increase community and individual concerns regarding confidentiality and privacy.

  Given the possibility of potential breaches in confidentiality, as well as the strong incentives of HMOs and other managed care entities and insurers to obtain such lists, it is critical that any system that is implemented make every effort to minimize—if not eliminate—the possibility of such disclosures. Any sort of named reporting of HIV infection clearly violates this principle and greatly increases the possibility for breaches and/or legislative mandate to disclose who is HIV infected. Finally, in order to minimize the potential for disclosure there should be extensive and enforceable penalties applied to anyone who tries to inappropriately access health department HIV case information or any health department personnel who disclose an individual's HIV status.

- **Not come at the expense of resources for treatment/services.** Although increased data could potentially be useful for planning and evaluation purposes, its benefit will be eliminated if resources for care or prevention services are re-directed to fund surveillance systems. Although surveillance data may be useful, it in no way supplants the need for adequate funding for HIV prevention and care services. In addition, the government must not use expenditures on HIV surveillance to indicate that something is being done to fight the epidemic. Counting cases is not equivalent to responding to the epidemic.

- **Respect individual choice with respect to name disclosure.** Any HIV surveillance system that is developed should provide individuals with the option not to have their names or other identifying information reported to the government. By ensuring this choice, the system will

reduce the potential for deterrence to testing and/or treatment as well as the likelihood of misuse of the information, thus minimizing the potential for negative consequences. This also helps to ensure that individuals living with HIV and those at risk for HIV infection have some control over the information that is available about them and minimizes the invasiveness of such surveillance systems. Given the mistrust of government in today's society, particularly among disenfranchised populations, individuals must be allowed to decide for themselves if they want identifying information provided to governmental entities.

Simply guaranteeing the availability of anonymous testing does not address this concern. If a names reporting system were instituted, individuals would have no control over the disclosure of their name when they accessed early treatment. The system must respect individuals' decisions about their names being reported or disclosed to public health authorities at not only the point of HIV testing, but also when individuals seek HIV care services.

Thus, mandatory names reporting should under no circumstances be required or encouraged. Other systems that do not rely on names, such as some type of unique identifier system that also meets the other criteria listed above, should be pursued if it is decided that HIV surveillance data is necessary and will be utilized in a manner that promotes the community's health.

The Foundation will remain opposed to any HIV surveillance system that does not meet the above criteria. Only by meeting these criteria will a system provide sufficient benefit to the community to outweigh any potential negative or damaging consequences.

Unique Identifier Reporting Must Be Examined as a Viable Alternative

The primary HIV surveillance system that is considered a potential alternative to names reporting is unique identifier reporting. Under such a system, an HIV-infected individual would not be reported by name to public health officials but rather by some form of a unique code that could not be traced back to the person. These types of systems use letters or numbers to represent data elements such as race, gender, and date of birth, which create a code with a high degree of uniqueness. Theoretically, this code is unique to the individual for whom it is developed (so that no one else is reported with the same identifier), and would be easily replicated every time the person is reported, thus ensuring an unduplicated count of HIV cases.

Unique identifier reporting has been seen as a potential compromise between those who strongly believe that better HIV data is needed and those who have strong public health and privacy concerns regarding HIV names reporting. Unfortunately, the experience with unique identifier reporting for HIV infection has been rather limited in the United States. Only two states—Maryland and Texas—have implemented such systems, and these have only been in place since 1994. Because these systems are the only ones that exist in the nation, they have been carefully scrutinized and compared to HIV names reporting systems in other states. Many have argued that the data regarding the effectiveness of these systems are not promising and have shown that these systems provide less complete information than that provided through names based reporting. This has led many to conclude that names reporting is the only viable HIV surveillance system available.

The Foundation disagrees with this conclusion. We do not believe that unique identifier reporting systems have been judged fairly in the national debate regarding HIV surveillance systems. Specifically:

- **Unique identifier systems have not been funded adequately.** While the CDC provides funding to states to implement names based reporting, relatively little financial support has been provided for unique identifier systems by either federal or state governments. Lack of resources has limited the ability to implement a system that is as effective as possible.

- **The evaluation of the current unique identifier systems has not adequately taken into account the fact that these systems are relatively new.** Both Texas and Maryland began implementing their systems in March of 1994, only a little over three years ago. The relative youth of these systems must be kept in mind when evaluating their effectiveness. These systems are bound to improve over time. To the extent that evaluations of these systems have shown potential problems, this information can and should be used to improve and build upon the existing systems and/or to assist in crafting new and better systems.

- **The standard used to judge unique identifier systems has been set unnecessarily high.** As noted above, absolutely complete and accurate data is not needed to analyze broad trends in the epidemic. Although the completeness of information provided by unique identifier reporting has not been as high as name-based reporting, it would certainly provide much more information than we currently have about emerging trends in the epidemic. This new data will significantly improve our ability to plan for upcoming health care and social service needs and appropriately target and evaluate prevention activities.

- **The fact that many states have implemented names-based reporting does not provide a legitimate rationale for opposing unique identifier reporting.** Some have argued that because 28 states currently require HIV names reporting, all other states should follow suit to ensure that there is a consistent reporting mechanism across the country. However, it is estimated that 75% of individuals living with HIV infection reside in states that do not require HIV case reporting by name. A national system must be designed to meet the legitimate public health needs of all states—including those with the largest percentage of people living with the disease.

The presumption that name-based reporting is the only effective system and the easiest to implement has led many to reject unique identifiers or other possible systems out-of-hand. The Foundation believes that if public health officials commit to providing proper attention and time to developing such a system, a reporting mechanism could be developed that would provide adequate and necessary surveillance data while greatly reducing the public health and privacy concerns related to name based reporting.

In conclusion, the Foundation certainly agrees that improved HIV surveillance data, if used appropriately, could benefit people living with HIV. However, collection of this data must be done in a manner that minimizes the potential for harm to these same individuals. We will continue to work to establish a system that meets both of these important goals.

prepared by Anna Forbes, MSS, AIDS and Women's Health Policy Consultant
phone: (610) 649-8113, e-mail: aforbes@critpath.org
September, 1997

MYTHS AND FACTS ABOUT HIV CASE REPORTING BY NAME VERSUS BY UNIQUE IDENTIFIER

The American Medical Association, the Council of State and Territorial Epidemiologists and the New England Journal of Medicine, among others, have recently started urging all states to adopt name-based reporting of HIV. This policy requires doctors, test sites and labs to report to their state Health Department the names of all individuals who test positive for HIV.

Some people who oppose Mandatory Name Reporting (MNR) of people with HIV believe that HIV case data should be collected using unique identifier codes instead of names. They argue that this enables epidemiologists to track HIV spread and study the epidemic without putting the privacy of people with HIV at risk by entering their names into a permanent state registry.

These are a few of the myths and facts about HIV case reporting by MNR unique identifiers:

MYTH: **If state Health Departments have the names, they can make sure that everybody who tests HIV positive gets into care early and has a chance to take advantage of medical advances in HIV treatment.**

FACT: In 1996 through early 1997, only 25% of Americans with CDC-defined AIDS were on any kind of Protease Inhibitor therapy. The federally funded AIDS Drug Assistance Programs (ADAP) got medication to somewhere between 14% and 28% of all ADAP eligible people in 1996. Even while serving a quarter of the eligible population, ADAP initiatives are going broke. Medicaid is clearly unable to afford triple combination therapy for all the Medicaid recipients with HIV who might benefit from it. How will collecting names get everyone into care when money to pay for the care obviously isn't available?

MYTH: **People with HIV don't have to worry about having their names in a state HIV registry because existing privacy laws protect them from discrimination.**

FACT: On September 11, 1997, Health and Human Services Secretary Donna Shalala recommended to the US Congress that police and other law enforcement officials be given unlimited access on request to all private medical records. If her recommendation is passed into law, it could very well give them legal access to name-based HIV registries. How do we know that this access won't be used by INS (since HIV positivity disqualifies an individual for legal immigration) or by police in states where laws exist that criminalize HIV under various

circumstances (such as "willful transmission" laws, sodomy statutes, etc.)?

State privacy laws are only as strong as the legislatures' will to uphold them. States can, and do, change their laws regarding privacy all the time. If a state Health Department has a name-based registry listing people with HIV, it can be forced at any time to open that registry by either legislative mandate or court order.

MYTH: **The fear that HIV name reporting will cause people to avoid getting tested for HIV turns out not to be true.**

FACT: The recently completed MESH (Multi-State Evaluation of Surveillance of HIV) study surveyed HIV positive and negative people in eight states about the attitudes and factors that influenced their HIV testing decisions. Nearly 20% of those surveyed listed fear of name reporting as one reason for avoiding HIV testing. Since 50% of HIV positive Americans don't know they are infected, anything that discourages testing to this extent should be a serious public health concern.

MYTH: **Health Departments need the names so that they can contact people and get the names of their sex and needle sharing partners for partner notification.**

FACT: The MESH study also disproved this. Of the HIV positive people surveyed in the MESH study, those tested at anonymous test sites (where names aren't used) supplied the same number of partner names on average as those tested at confidential test sites (where names are collected). In partner notification, it is the *partners* who are contacted during follow up. Thus, the name of the person testing positive is not needed in order for effective partner notification to be done.

MYTH: **Unique identifier-based reporting systems are uniformly inefficient and inadequate for HIV case reporting.**

FACT: Unique identifier-based HIV case reporting is done in the U.S. by Maryland and Texas and abroad by France, Denmark and Australia. The Maryland Health Department, to give one example, reports that its system accurately monitors statewide HIV trends and has achieved 96.6% completeness in reporting by state-funded HIV test sites. Completeness rates from other testing sites (hospitals and private physicians) are lower but steadily improving.

It is a mistake, however, to evaluate unique identifiers in general by looking at one or two systems. A wide variety of unique identifier systems are available. They vary widely in efficiency and effectiveness at protecting privacy. Some make it hard to prevent duplication of records, for example, while others ensure a lower duplication rate than is achievable with names. Some unique identifier codes are easy to "crack" (decipher to obtain the person's identity) and some are virtually impossible to crack. Each system has to be weighed on its own merits.

MYTH: **Unique identifier systems are too expensive.**

FACT: HIV case reporting costs money to implement, whether names or unique identifiers are used. Maryland and Texas set up their systems after receiving one-time CDC grants of $600,000, allocated to evaluate the systems over three years. Both states report that the difficulty of mounting a unique identifier system was exacerbated by the total lack of state funding, among other factors. Maryland now processes 7500 unique identifier-based HIV reports per year with a system that costs about $100,000 per year in staff, equipment and supplies to operate.

New York's Health Department spends a comparable, per-case amount on name-based reporting of low CD4 test results. To follow up on approximately 14,400 low CD4 reports per year, New York had to add four FTE's (two research specialists and two public health representatives) to its HIV/AIDS surveillance staff as well as a 1/4 FTE for ongoing computer system maintenance and improvement. These staffing costs can be assumed to total $200,000 or more.

MYTH: **Since most of the states have Mandatory Name Reporting, the rest of the states might as well go along with it.**

FACT: 30 states already have some form of MNR for people with HIV. All but two of these, however, are not high incidence states. The CDC estimates that 75% of all US residents with HIV are living in the high incidence states and territories that *don't* yet require HIV case reporting by name. These are California, Georgia, Illinois, Maryland, New York, Pennsylvania, Puerto Rico and Texas.

Whether these places adopt MNR or not will depend on the level of resistance to it generated by the consumer, civil rights and activist communities. A number of national organizations including the National Association of People with AIDS (NAPWA), the National Minority AIDS Council and the National Lesbian and Gay Health Association are already on record as opposing MNR for HIV.

prepared by Anna Forbes, MSS
AIDS and Women's Health Policy Consultant
(610)649-8113 or aforbes@critpath.org

BRIEF OVERVIEW OF SOME UNIQUE IDENTIFIER SYSTEM ALTERNATIVES

The following are some of the Unique Identifier (UI) systems now in use for HIV/AIDS and other forms of health reporting. This is a very preliminary list presented for discussion purposes only and should not be viewed as an exhaustive compilation of all the options.

Least Protective of Privacy

Names are a relatively unique identifier. Everybody has one although duplicates certainly exist. They are not private.

Social Security Number: This was created to be a UI solely for use by the Social Security Administration. Now it is in use everywhere and, thus, offers almost no privacy.

More Protective of Privacy

HRSA's Unique Record Number System for CARE Act services reporting:

Created in 1992 by Mathematica for the federal government. Code comprised of the following data elements:

- First name
- Last name
- Date of Birth
- Gender

Code is created by services provider.

Maryland's Unique Identifier System:

Created by the state of Maryland for HIV case reporting. Code is comprised of the following data elements:

- Last four digits of Social Security Number
- Date of Birth
- Race/ethnicity
- Gender

Code is created by HIV testing provider and reported to state by labs for all HIV positive test results.

Texas' Unique Identifier System:

Created by Texas for HIV case reporting. Code is comprised of the following:

- Last four digits of Social Security Number
- Date of Birth
- Race/ethnicity
- Gender

Data elements are sent by testing providers to the state Health Department which then creates the UI codes.

New York system for recording woman's identify **on Fetal Death Certificates**:

Created by New York in 1992. Codes are comprised of the following data elements:

- First name
- Last name at birth ("maiden" name)
- date of birth
- gender
- last four digits of Social Security Number

Most protective of privacy

Any system that incorporates a private data element into the mix of data elements used to produce a UI is more protective of privacy than one using entirely public record data elements. Two such systems have been created in connection with HIV reporting.

Client Key System:

Created in Philadelphia in 1992 and field tested in 10 CARE Act funded services sites in Pennsylvania in 1992-93.

Code comprised of the following data elements:

- Name
- Date of Birth
- Gender
- Key word or phrase selected by client

Code is created by services provider.

DoubleLock System:

Hypothetical system invented in Philadelphia. Not yet implemented or field tested.

Code comprised of the following data elements:

- Name
- Date of Birth
- Gender
- Standardized measurement of ratio of hand size

Code would be created by services provider.

July, 1997

A Brief Overview of the Unique Identifier System Used by the Maryland Department of Health and Mental Hygiene for HIV and CD Reporting

Why Was It Created?

Maryland's unique identifier (UI) system was created following passage of House Bill 375 in 1993. Three years in a row (1992, 93 and 94), mandatory name-based HIV reporting legislation had been introduced in Maryland's General Assembly and defeated as a result of vigorous community opposition to it. So this UI system was developed in an atmosphere of strong community insistence on UI-based, rather than name-based, reporting.

What Criteria Were Used in Creating It?

Maryland assigns a UI to each person being tested for HIV infection or CD4 count. Since the UI is regenerated (created in the same way each time with the same results), individuals receive the same UI code every time they get tested, regardless of provider (whether in a physician's office, hospital or community test site).

The Department established the following criteria in preparation for creating this UI system. They decided that it had to:

- be simple to generate (i.e. does not require access to a computer, does not take more than 90 seconds per code to generate, does not require staff to make subjective determinations)

- have data elements that are immutable (don't change over time)

- be generated from factual information (data elements) provided by the client

- have a duplication rate no greater than 2% (less than 2 chances in 100 that one person will be assigned two different codes and, thus, counted twice)

- not be easily "cracked" (not permit easy identification of the individual to whom a code was assigned)

- not depend on an individual's ability to recall and accurately report a previously assigned code

What Are the Department's Objectives for the System?

The Department sees the UI system as enabling them to accomplish two main objectives:

1) monitoring trends in HIV infection throughout the state accurately and

2) enabling the Department to conduct case identification as needed of individuals with symptomatic HIV infection and AIDS.

What Are the UI Components?

Maryland's UI is a 12-digit number consisting, from left to right, of:

Last four digits of client's Social Security number

Client's Date of Birth (in the form MMDDYY)

Client's race/ethnicity (using the same coding scheme as appears on the CDC's HIV/AIDS Care Reporting Form)

Client's gender (also as coded on the CDC's Reporting Form)

So, for example, an African-American man born on February 4, 1952 and with a Social Security number of 678-01-1234 gets a UI of 123402045221

Does Everyone Have to Use UI's?

All providers of HIV and CD4 testing are required to assign UI's to test recipients and to report HIV positive and low CD4 test results to the Maryland Health Department by UI. Labs are also required to report these test results by UI. The only people exempted from these reporting requirements are:

- blood, tissue and semen donors
- people known to reside outside of Maryland
- those receiving testing at Health Department designated anonymous test sites

- people participating in IRB-approved research in which specimens are blinded and/or in research not primarily intended to provide medical treatment to participants

- people participating in research approved by an IRB located outside of Maryland

How Much Did Conversion To It Cost and How Was It Funded?

No state dollars have been allocated to either the creation or the implementation of this system. The only federal dollars allocated to it were in the form of a 1993 CDC Cooperative Agreement to evaluate the system, once functional. Prior to implementation, the Maryland Register (Vol. 21, Issue 3, 2/4/94) reported the estimated economic impact to state and local agencies of establishing the new system as $167,750.

By way of comparison, it must be noted that there are also costs inherent in implementation of name-based reporting. New York State AIDS Institute administrators reported in 1996, for example, that when New York adopted name-based reporting of low CD4 test results, they had to make staffing allocations equivalent to two full time program research specialists and two full time public health representatives -- just to work on CD4 follow up. This was in addition to the intensive research design work that went into creating their system for name-based reporting which consumed approximately ½ FTE (in high level research design) for a period of at least six months and now requires about 1/4 FTE for system maintenance and improvement.

How Well Does Maryland's System Work?

Dr. Liza Solomon of the Department's AIDS Administration office reports that the UI system, now in Year 3, must be viewed as still immature (as was name-based AIDS Surveillance in its third year of existence, circa 1985).

The greatest area of difficulty is still in getting all provider to report all UI's completely and accurately. She notes, however, that they have achieved 96.6% completeness in reporting by state-funded counseling and testing site over a two year implementation period. She attributes this to the fact that the Department recruits, trains and funds staff at these sites and, thus, is better able to achieve high levels of compliance from them.

Compliance by hospitals and private providers has not been as high but is steadily improving. The overall rate of missing UI components dropped from 35% to 16% in all categories but one

between Year One of implementation and Year Three. The overall number of incomplete UI's also dropped by half between Years One and Three.

There is still as 23% missing data rate in the category of Social Security number. Dr. Solomon observes that, "in retrospect, states contemplating a UI system may want to re-think use of the Social Security number, although it does help with linking with other data bases."

Does This UI System Link with Other Data Bases?

It links completely with the HARS AIDS Reporting System, the HIV Counseling and Testing Sites Data Base (Maryland's CTS reporting form includes the UI), death certificates, the ADAP data base and other special investigational data bases. It does not link, however, with Maryland's TB registry and the Hospital Discharge Summaries; ICD9 coding nets.

What Is the Advocacy and Consumer Communities Response to the UI System?

The PWA/HIV Coalition of Baltimore, AIDS Action Baltimore, the Baltimore-based AIDS Research Information Center (ARIC) and the AIDS Legislative Committee agree than name-based reporting scares people away from HIV testing and early intervention services. Says ARIC Executive Director Lee-Angel Hardy, "The only way we're going to get the dollars we need, especially in a Republican Administration, is with the numbers, the data." He adds that Maryland's unique identifier reporting system was created because advocates recognized this but were unwilling to tolerate the dangers posed by name-based reporting.

"It was a very arduous compromise between the advocates and the governor," says Michele Douglas of the AIDS Legislative Committee (in reference to then-Governor Schaefer). "But in the long run, the UI system balances the stated needs of both groups." Douglas added that system allays consumer concerns about case reporting and that, as far as they can tell, effectively prevents the testing and care avoidance that are demonstrably associated with name-based reporting.

Overview prepared by Anna Forbes, MSS, AIDS and Women's Health Policy Consultant, Ardmore, PA, (610) 649-8113, aforbes@critpath.org

Principles for the Protection of Health Information Privacy

NAPWA

NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

The United States has made great strides in improving its understanding of people living with HIV and millions of people are committed to caring for and supporting the nearly one million people believed to be living with HIV in the United States. Nonetheless, HIV disease and AIDS remain deeply stigmatizing. The National Association of People with AIDS (NAPWA) believes that individuals must retain the right to control the disclosure of their health status. NAPWA also believes that individuals must be the primary decision-makers regarding their own health care matters and that health status cannot be permitted to be used to victimize people. For this reason, NAPWA strongly supports federal action to statutorily establish a right to privacy of an individual's health information.

The Health Insurance Portability and Accountability Act of 1996 included provisions to allow for the electronic dissemination of health information. This legislation even recognized the need for consumers to have protections against unauthorized disclosure of their medical records, by setting a time frame in which the Congress must act on this issue or the Secretary of Health and Human Services is directed to promulgate regulations to protect the privacy of an individual's health information. As Congress and national policy makers grapple with complex issues related to the privacy of health information, NAPWA affirms its support for the following principles:

Federal legislation should statutorily establish an individual's right to privacy with respect to individually identifiable health information, including genetic information. Individuals should retain the ultimate right to decide to whom, and under what circumstances, their individually identifiable health information will be disclosed. Confidentiality protections should extend not only to medical records, but also to all other individually identifiable health information, including genetic test results, clinical research records, mental health therapy notes, etc.

Federal legislation should prohibit the use or disclosure of individually identifiable health information absent an individual's informed consent. Health care providers, insurance companies, and others in possession of individually identifiable health information should be prohibited from using or disclosing such information unless authorized by the individual. In addition, any information used or disclosed should be limited to the minimum amount necessary for the use or disclosure. Unauthorized disclosures should be permitted only under exceptional circumstances--for example, if a person's

1413 K Street, N.W., Washington D.C. 20005
Phone: (202) 898-0414
FAX: (202) 898-0435

life is endangered, if there is a threat to the public health, or if there is a compelling law enforcement need (as evidenced by a warrant or court order mandating access to a specific individual's records).

Federal legislation should guarantee an individual the right to access his or her own health information and the right to amend such information. Individuals should have the right to access and amend their own medical records so that they can make informed health care decisions and can correct erroneous information in their records.

Federal legislation should establish strong and effective remedies for violations of privacy protections. Remedies should include a private right of action, as well as civil penalties and criminal sanctions, where appropriate.

Federal legislation should provide a floor for the protection of individual privacy rights, not a ceiling. Like all other federal civil rights and privacy laws, federal privacy legislation for health information should set the minimum acceptable standard. Federal legislation should not pre-empt any other federal or state law or regulation that is more protective of an individual's right to privacy of or access to individually identifiable health information.

While protecting individual privacy rights, federal legislation should not impede important clinical and medical research. Federal privacy protections should not hinder the conduct of biomedical research and development. For example, researchers should be allowed to continue using existing anonymized patient databases and tissue samples. We believe, however, that "research" should not be defined so broadly as to permit the disclosure of individually identifiable health information for marketing or commercial purposes.

(September 1997)

the National Association of People with AIDS

1413 K Street, NW
Washington, DC
20005-3405
tel (202) 898-0414
fax (202) 898-0435
NAPWA FAX
(202) 789-2222
E-mail address:
napwa@thecure.org
Home page address:
http://www.thecure.org

Policy Position Paper
on
Monitoring of the HIV Epidemic

Position

The following criteria define NAPWA's position on the responsible and ethical approach to monitoring the HIV/AIDS epidemic in the United States. Collectively, these fourteen criteria define a comprehensive approach to both our nation's surveillance system and our nation's HIV counseling and testing system, as well as federal public policy and civil rights concerns.

1. Under no circumstance does NAPWA support HIV named reporting, the CDC's promotion of a national standard in support of HIV named reporting or the creation of a federal name-based registry of people living with HIV/AIDS. The CDC should in no way encourage or require states to do HIV named reporting.

2. NAPWA guardedly supports the expansion of our national HIV/AIDS surveillance system to include HIV infection case reporting; however, only using unique or coded identifiers that insure privacy and confidentiality of the individual.

3. The CDC must aggressively promote, expand and improve anonymous HIV testing in the United States. The availability of readily accessible anonymous testing is a necessary condition/prerequisite for any maintenance and/or expansion of HIV surveillance in the United States. CDC must mandate readily accessible anonymous testing in all HIV Prevention Cooperative Agreement jurisdictions as a condition of establishing HIV surveillance tools nationally.

4. CDC-funded research has shown that certain individuals and/or communities will only use anonymous testing sites. Therefore, access to primary care (after testing positive) is predicated upon the availability of anonymous testing.

5. CDC's HIV/AIDS surveillance's primary goal is to collect useful data in a timely fashion to provide an accurate estimate of the prevalence of HIV/AIDS in the United States. Accordingly, HIV/AIDS surveillance has to provide reliable data. As such, while it is a goal of anonymous and confidential counseling and testing to link individuals into services, this is not necessarily either a goal or an outcome of surveillance.

6. The applied uses of reliable, accurate and timely surveillance data include informing: resource allocation; health planning; and evaluation of both programmatic as well as system-wide activities (i.e. access to care, survival/death rates, seroincidence rates, etc.).

7. As a guiding principle, unless a name is uniquely essential for the protection and promotion of an individual's health and well-being or a community's health and well-being, the name of the person whose information is being reported to the state or local health department should not be taken.

8. Surveillance is an adaptive science. As such, surveillance systems should be constantly re-evaluated to determine if the goal of applying surveillance data to meaningful education, programs, planning and resource allocation is happening. If not, these systems should be discontinued.

9. Surveillance systems consist of several different types of activities **in addition** to case counting (number of individuals living or deceased who have said disease): sentinel studies; incidence and prevalence studies (density of disease and breadth of disease); and even behavioral (risk-taking) surveillance. The more varied the surveillance system, the more relevant the data sets that result.

10. Decisions regarding what type of HIV/AIDS surveillance to implement in a given jurisdiction are best made by each jurisdiction based on resources, community acceptance, confidentiality/privacy protections, the severity of the epidemic, and other local considerations.

11. Data from HIV case reporting must be appropriately disseminated to the community planning bodies within jurisdictions for use in both prevention and care planning.

12. Categorical funding for HIV/AIDS surveillance must be maintained and augmented. However, resources for HIV/AIDS surveillance must not come at the expense of resources for HIV-related research, care and prevention (both primary and secondary) programs.

13. National HIV/AIDS public health policy should reinforce that the data collected under this system must remain decoupled from partner notification and contact tracing processes. These processes' relationship to surveillance must be made only as a component of and only with the explicit concurrence from the jurisdiction's HIV Prevention Community Planning group.

14. Federal law must establish an individual's enforceable right to privacy with respect to individually identifiable health information, and must protect each person from discrimination based on real or perceived health and/or genetic status. Such laws must include strong and enforceable repercussions for those individuals and systems that breach an individual's confidentiality and/or privacy.

(October 3, 1997)

Policy Statement

ID-4. HIV SURVEILLANCE

4.1 PREAMBLE

National surveillance and other information systems for HIV/AIDS have been crucial elements of local, state, and federal strategies to prevent HIV infection. In 1997, developments such as the first ever decline in AIDS deaths, due in part to powerful new therapies available, caused many public health officials to re-evaluate the way in which surveillance is performed for HIV/AIDS. Therefore, ASTHO promotes the following policies with regard to HIV/AIDS surveillance:

4.2 All states should perform HIV surveillance. Surveillance helps to obtain a minimum estimate of the number of HIV infected persons; to monitor recent epidemic infection trends; to evaluate prevention interventions; to provide epidemiological profiles for community planning; to provide referrals to care and services; and to increase efficiency of surveillance systems by relying solely on laboratory-based test results instead of clinical results (such as an AIDS-defining illness or opportunistic infection).

4.3 ASTHO recommends that all states undertake named HIV reporting. However, ASTHO opposes any federal mandate to collect the names of HIV positive persons. Any reporting of names of individuals with HIV infection should not be a condition of federal AIDS funding.

4.4 CDC, in consultation with states, should identify the core data elements needed in an HIV surveillance system. These data elements might include information on newly diagnosed cases (measured by persons with acute/primary HIV infection, recent seroconverters, or high CD4+ cells), late-stage disease (AIDS), and HIV-related deaths.

4.5 CDC should provide sufficient funds and technical assistance to ensure the quality and efficiency of HIV surveillance systems.

4.6 CDC should continue to use population-based HIV surveillance such as STD clinic and drug treatment center blinded studies. HHS should also reinstate the survey of HIV seroprevalence in childbearing women.

4.7 CDC should provide technical guidance to states and localities to devise a system for periodic review and improvement of confidentiality protections. Discrimination laws to protect HIV positive individuals from discrimination in employment, housing, public accommodations, and other areas should be vigorously enforced.

4.8 **Anonymous testing is not incompatible with HIV surveillance for any state/community which deems that provision of anonymous testing is an important part of its HIV prevention plan.** The decision regarding the provision of anonymous testing in a given jurisdiction should be made by public health officials and HIV prevention community planning groups.

4.9 **Partner notification efforts should not necessarily be linked to HIV surveillance. Voluntary partner notification programs should be developed in a broader context of community planning for HIV prevention.** Partner notification issues have been discussed in the context of HIV surveillance; however, partner notification programs and surveillance programs are discreet public health functions which do not necessarily need to be linked together. Decisions regarding partner notification programs should be made by public health officials and HIV prevention community planning groups.

Policy Expires on December 31, 2000
Recommended for Adoption by the ASTHO Infectious Disease Committee on August 25, 1997
Adopted by the ASTHO Executive Committee on September 2, 1997
Ratified by ASTHO Membership on September 25, 1997

October 24, 1997

Privacy in H.I.V. Reporting

The Centers for Disease Control makes a good case for mandatory reporting of all cases of H.I.V. infection. But any reporting plan must protect the privacy of infected individuals.

Although every state requires that AIDS cases be reported to health authorities, only 26 states collect such data on individuals infected with H.I.V. who have not yet developed AIDS. New York, for example, does not require H.I.V. reporting.

New medical advances that delay the onset of symptoms and reduce death rates have so altered the epidemic that collecting data on only those in the advanced stages of the disease is now inadequate. A national reporting requirement would allow authorities to track the disease better, target prevention services to vulnerable populations and allocate medical resources more effectively.

Even so, great care must be taken to protect individual privacy. Many fear that their H.I.V. status, if it became known, could be used against them in employment, housing and health insurance. Unless confidentiality can be guaranteed, a reporting requirement will very likely deter people from being tested and seeking medical care.

One way to avoid unauthorized disclosure of sensitive information is to use anonymous coded identifiers in reporting H.I.V. patients instead of their names. This approach may be more costly to set up and manage, but it would insure strict security of reported information. A proposal with weaker privacy protections would undermine efforts to promote early testing and treatment.

National Organizations Responding to AIDS (NORA)
MEMORANDUM

TO: NORA Coalition

FROM: Chad Lord, NORA Coordinator
AIDS Action Council, 202-986-1300, ext. 3062

DATE: 4 November 1997

REASON: Upcoming Working Group Meetings

Health Access Working Group, Thursday, November 6, 1997, 3:30pm, at Powell, Goldstein, Frazer, and Murphy, 1001 Pennsylvania Ave., NW, Sixth Floor
For more information, contact: Amy Andersen, AAC 202-986-1300
Julie Rocchio, NAPH 202-624-7255

Incarcerated Populations Working Group, Tuesday, November 4,1997, 2:00pm, at the ACLU Prison Project, 1875 Connecticut Ave., NW, Suite 410
For more information, contact: Jackie Walker, ACLU Prison Project, 202-234-4830

National Organizations Responding to AIDS (NORA)

November 4, 1997
9:30am -12:00pm

American Nurses Association
600 Maryland Ave., SW, Suite 100 West
Washington, DC 20024

Special Coalition Meeting
HIV Surveillance

AGENDA

I. *Introduction and purpose of the meeting* – Miguelina Maldonado, Co-chair, and David Harvey, Co-chair, NORA Executive Committee

II. *Presentations*

a. Kevin DeCock, Centers for Disease Control and Prevention

b. Mike Adams, American Civil Liberties Union

c. Gus Birkhead, M.D., Council of State and Territorial Epidemiologists

d. Miguelina Maldonado, National Minority AIDS Council

BREAK – 15 MINUTES

III. *Discussion, questions and answers* – moderated by David Harvey, Co-chair, NORA Executive Committee

WH threatening to veto based on Goodling amendment — would force us into CR — threaten AIDS funding

possibility of re-visiting legislative or reporting language?

What are conditions in report language?

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

October 31, 1997

Dear Colleague:

As you know, there has recently been a great deal of discussion about the need for improved HIV surveillance, with much of the debate focusing on the issue of names reporting. In the upcoming months, the U.S. Centers for Disease Control and Prevention (CDC) is expected to issue guidelines encouraging all states to implement an HIV reporting system, and will most likely give preference to a name-based system. After the first of the year, we also expect the introduction of state legislation to mandate reporting of HIV cases by name to public health officials in California.

In anticipation of these potential developments, the San Francisco AIDS Foundation recently issued the enclosed position statement on HIV surveillance and reporting. We hope that you will read it though, and that it will inform your own thinking about this important policy debate.

In summary, while the Foundation agrees that there is a need for improved HIV data -- *if* this information is in fact used to better plan for future service needs and to target and evaluate prevention efforts -- we continue to disagree strongly that HIV *names* reporting is necessary to accomplish this goal, particularly given the potential negative repercussions associated with this type of reporting system. We believe that another HIV reporting system could be developed -- such as reporting via a unique identifier code -- that would not raise the same public health and privacy concerns associated with HIV names reporting. In addition, we absolutely reject the popular misconception that names reporting is necessary in order to improve access to new treatments.

Other advocacy organizations, including the National Association of People with AIDS (NAPWA), AIDS Action Council, AIDS Action Committee of Boston and the American Civil Liberties Union (ACLU) have recently issued similar statements because of concerns about names reporting.

Based on our position statement, the Foundation will advocate adoption of local, state and national surveillance systems that provide useful data while minimizing any potential harm to individuals living with HIV. If you have additional questions, please feel free to contact the Public Policy Department at (415) 487-3080.

Sincerely,

Regina Aragón

Regina Aragón
Deputy Director for Public Policy

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

EXECUTIVE SUMMARY OF THE HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION

Changes in the epidemic have led many public health officials to express increasing concern that existing AIDS surveillance efforts are becoming outdated. This has often resulted in the call for some type of HIV reporting system.

The San Francisco AIDS Foundation acknowledges there is a need for improved HIV data, if this information is used appropriately to better plan for future service needs, target and evaluate prevention efforts, and inform resource allocation decisions. **However, we strongly disagree that HIV *names* reporting is necessary to accomplish these goals, and we do not believe that the benefits of names reporting outweigh the potential negative repercussions associated with this type of surveillance system (such as the possibility that some individuals would be deterred from seeking HIV testing and/or treatment under such a system).**

Any system that is developed should meet the goals of HIV surveillance and the criteria by which HIV surveillance systems should be evaluated that are outlined below. Non-names based surveillance systems that may be able to meet these goals and criteria, such as reporting systems that utilize unique identifiers, must be more aggressively examined in an unbiased fashion as a viable alternative to HIV names reporting.

Goals and Appropriate Uses of HIV Surveillance Data

We believe that HIV surveillance should only be designed to help meet the following goals:

- Better determine and understand the demographic and risk profiles of the current epidemic;
- Plan for future health care and social service needs;
- Track new incidence of HIV in order to target prevention efforts;
- Evaluate overall efficacy of prevention efforts;
- Inform rational resource allocation.

Any HIV surveillance system that is developed should include specific mechanisms to ensure that surveillance data is utilized to meet these goals. In addition, although certain activities are worthy goals of HIV testing and treatment programs—such as linking individuals to care and treatment or identifying additional individuals who have possibly been exposed to HIV—these are not appropriate uses of HIV surveillance data. HIV reporting will not make treatment more available or accessible and is not needed to conduct effective partner notification.

Criteria That Should Be Utilized to Evaluate HIV Surveillance Efforts

The Foundation believes there are reasonable and appropriate criteria that must be met to justify the use of any particular HIV surveillance system. Specifically, an HIV surveillance system should:

10 UNITED NATIONS PLAZA
SAN FRANCISCO, CALIFORNIA 94102-4901
(415) 487-3000

- Not create a disincentive to testing and/or treatment;
- Produce information that is actually utilized for planning and evaluation purposes in a manner that has the potential to improve the community's health;
- Not violate confidentiality and/or civil rights and should include strong enforcement and penalties for disclosure of information;
- Not come at the expense of resources for treatment/services:
- Respect individual choice with respect to name disclosure.

Only by meeting these criteria will a system provide sufficient benefit to outweigh any potential negative or damaging consequences. A mandatory name-based reporting system would run counter to several of these criteria and should under no circumstances be required or encouraged. Other systems that do not rely on names, such as some type of unique identifier system, should be pursued if it is determined that such a system also meets these criteria.

Unique Identifier Reporting Must Be Examined as a Viable Alternative

The primary HIV surveillance system that is considered a potential alternative to names reporting is unique identifier reporting. Under such a system, an HIV-infected individual would not be reported by name to public health officials, but rather by some form of a unique code that could not be traced back to the person. Many have argued that the data regarding the effectiveness of unique identifier systems show that these systems are inadequate and that names reporting is the only viable HIV surveillance system available. The Foundation disagrees with this conclusion. We do not believe that unique identifier reporting systems have been judged fairly in the national debate regarding HIV surveillance systems. Specifically:

- Unique identifier systems have not been funded adequately.
- The evaluation of the current unique identifier systems has not taken into account the fact that these systems are relatively new.
- The standard used to judge unique identifier systems has been set unnecessarily high. Absolutely complete and accurate data is not needed to analyze broad trends in the epidemic.
- The fact that many states have implemented names-based reporting does not provide a legitimate rationale for opposing unique identifier reporting (in fact, approximately 75% of individuals living with HIV reside in states that do not report HIV cases by name).

The Foundation believes that if public health officials commit to providing proper attention and time to developing such a system, a reporting mechanism could be developed that would provide adequate and necessary surveillance data while greatly reducing the public health and privacy concerns related to name based reporting.

In conclusion, the Foundation agrees that improved HIV surveillance data, if used appropriately, could benefit people living with HIV. However, collection of this data must be done in a manner that minimizes the potential for harm to these same individuals. We will continue to work to establish a system that meets both of these important goals.

For a copy of the complete, seven-page position statement, please contact the San Francisco AIDS Foundation Public Policy Department at (415) 487-3080.

SF AIDS FOUNDATION

SAN FRANCISCO AIDS FOUNDATION P.O. BOX 426182, SAN FRANCISCO, CALIFORNIA 94142-6182

HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION

Introduction

Changes in the epidemic have led many public health officials to express increasing concern that existing AIDS surveillance efforts are becoming outdated. Because new treatment options are thankfully slowing or stopping disease progression in many individuals living with HIV, greater numbers of individuals are not progressing to AIDS. These individuals are therefore not being reported systematically to public health entities (since in California and many other states, only AIDS cases are reportable). As a result, some public health officials have argued that AIDS case data are becoming less indicative of both the number and the demographics of individuals who are actually HIV-infected. Often, this has led to the call for HIV names reporting, whereby all individuals living with HIV would be reported by name and other identifying information to their local and/or state health departments.

The San Francisco AIDS Foundation acknowledges there is a need for improved HIV data, if this information is used appropriately to better plan for future service needs, target and evaluate prevention efforts, and inform resource allocation decisions. **However, we strongly disagree that HIV *names* reporting is necessary to accomplish these goals, and we do not believe that the benefits of names reporting for people living with HIV outweigh the potential negative repercussions associated with this type of surveillance system (such as the possibility that some individuals would be deterred from seeking HIV testing and/or treatment under such a system).**

Although the Foundation remains strongly opposed to mandatory names reporting, other HIV surveillance and/or reporting systems may be available or developed that could provide better data regarding the HIV epidemic without having the potentially negative impact of names reporting. This could include some type of HIV reporting by unique identifiers, in which an individual is assigned a unique and confidential code that is reported, expanded use of seroprevalence and seroincidence studies, or some other type of surveillance mechanism.

The remainder of this document outlines what we believe are the goals and appropriate uses of HIV surveillance systems, as well as criteria that should be used to judge any HIV surveillance system that is implemented. Non-names based surveillance systems that may be able to meet these goals and criteria, such as reporting systems that utilize unique identifiers, must be more aggressively examined in an unbiased fashion as a viable alternative to HIV names reporting.

Goals and Appropriate Uses of HIV Surveillance

We believe that HIV surveillance should only be designed to help meet the following goals:

- **Better determine and understand the demographic and risk profiles of the current epidemic.** Relying exclusively or primarily on AIDS reporting and surveillance makes it difficult to obtain a current "snapshot" of the HIV epidemic, and this is becoming even more problematic as fewer individuals are progressing to AIDS. However, it should be noted that HIV reporting data would be limited in that it would only provide information on those who self-select to be tested at a site where they are reported to government officials and/or those who seek health care for their HIV status. This data would in no way provide comprehensive information on all individuals who are HIV-infected.

- **Plan for future service needs.** The data gathered through HIV surveillance have the potential to provide community planners, leaders, and advocates with information to better assess and plan for upcoming healthcare and support service needs for people living with HIV/AIDS.

- **Track new incidence of HIV in order to target prevention efforts.** Ideally, HIV surveillance data could help us to better identify who is currently becoming infected (i.e. which risk behaviors and/or populations) and identify new trends in the epidemic, so that prevention efforts could be more quickly directed to those individuals at greatest risk for infection.

- **Evaluate overall efficacy of prevention efforts.** Surveillance information could also be used to help in broadly assessing the effectiveness of HIV prevention strategies. If HIV surveillance demonstrates that HIV infections are continuing to increase in a community, this may indicate a need to re-evaluate, alter and/or expand prevention efforts.

- **Inform rational resource allocation.** This data and its ability to assist in planning for future needs and targeting and evaluating prevention efforts could also be used to better inform resource allocation decisions. Surveillance data has the potential to inform both HIV-specific decisions (e.g., to determine funding for different HIV-specific services or for particular HIV-affected populations) and to inform broader, non-HIV specific funding decisions (e.g., determining spending for HIV and/or health care broadly as compared to other services or issues).

Any HIV surveillance system that is developed should include specific mechanisms to ensure that surveillance data are utilized to meet these goals. Far too often, surveillance systems have been developed that do nothing more than collect data, but are never actually used in a meaningful way to plan for improved service delivery or to inform the resource allocation process. It is unacceptable to collect this data without it clearly being used to meet goals that will benefit individuals living with HIV/AIDS. If the data collected through an HIV surveillance and/or reporting system are not actually utilized for these purposes or fail to meet these goals, the

surveillance system should be terminated and any resources being used to implement such a system should be redirected to other urgent health care needs.

In addition, the Foundation believes that the goals listed above are the *only* legitimate and justifiable goals of HIV surveillance. Other ways in which HIV surveillance information could be used have been identified, such as increasing direct access to HIV care and treatment and identifying additional individuals who have possibly been exposed (e.g. partner notification efforts). Although these are worthy goals of HIV testing and treatment programs, the Foundation does not agree that these are appropriate goals for HIV surveillance. Specifically:

- **HIV surveillance and/or reporting will not make treatment more available or accessible.** Instead, adequate funding levels of HIV care and treatment services are needed to expand access to new HIV treatments. San Francisco serves as an exemplary model for getting individuals tested and into early treatment and care not because of any sort of HIV reporting system, but because the City has assured adequate funding for these services. HIV surveillance or reporting will not in any way expand or improve access to care services.

- **HIV reporting is not needed to conduct effective partner notification.** Partner notification programs are already in place throughout California without any type of HIV reporting. If an individual is offered counseling on how to tell his or her previous partners about possible exposure to HIV or given the opportunity to have the local health department notify these partners, there is no need to have the initial case reported to the government. In fact, HIV reporting by name could actually *discourage* partner notification efforts because some individuals might be more reluctant to provide information about their partners if they know that their own name is going to be reported to a governmental entity.

Surveillance and reporting efforts have also been justified or used in extraordinarily inappropriate ways that actually harm or punish people living with HIV/AIDS. Specifically, HIV surveillance or reporting systems must be designed so that they can never be utilized to: (1) quarantine those with HIV; (2) penalize and/or criminalize individuals accused of transmitting or exposing others to HIV; or (3) assist in coercive efforts to mandate use of HIV treatments. In addition, these systems should never be used to create and/or maintain a perception the government is appropriately and adequately responding to the epidemic. HIV surveillance and/or reporting funding should in no way replace current prevention efforts or care and treatment services.

Finally, some have argued that HIV should be reportable in order to ensure that standard public health tools are applied to HIV. The Foundation does not believe that this justification, in and of itself, is a necessary or important goal. Unless applying standard public health tools to HIV actually meets the appropriate goals of HIV surveillance that are identified above, there is not an inherent value to applying these tools. Furthermore, these public health tools have not proven themselves to be unilaterally effective in stemming the spread of other diseases and their usefulness must be evaluated in regards to each particular public health issue. Any system that is implemented should be designed in a way that acknowledges both the strengths and weaknesses of "traditional" surveillance systems and public health methods.

Criteria That Should Be Utilized to Evaluate HIV Surveillance Efforts

As noted above, the Foundation agrees that improved surveillance efforts have the potential to improve HIV prevention efforts as well as care service delivery and planning. However, we also recognize that these same systems can have negative consequences for people living with HIV and those at risk for HIV infection, such as deterring individuals from seeking testing and/or treatment, shifting resources from other HIV services into surveillance, and violating individuals' confidentiality and/or civil rights. It is absolutely critical that we examine the trade-offs between obtaining better data and possible negative impact of this process. Thus, there must be a careful examination of any surveillance or reporting system that is proposed.

The Foundation believes there are reasonable and appropriate criteria that must be met to justify the use of any particular HIV surveillance system. Specifically, an HIV surveillance system should:

- **Not create a disincentive to testing and/or treatment.** Several studies have shown that some HIV reporting systems (in particular, names reporting) may reduce people's willingness to get tested. Given that an estimated one-third of those believed to be HIV-infected have never been tested, surveillance systems should not in any way discourage individuals at high risk for HIV infection from being tested. Specifically, anonymous testing must remain accessible and available to anyone who would prefer this testing option. Anonymous testing must be accessible geographically (i.e., individuals should not have to travel great distances to obtain anonymous testing), at convenient hours (including times in which individuals are not working), and should be provided free of any charges or fees.

  However, the availability of anonymous testing is not sufficient to address these concerns. Some individuals might get tested anonymously, find out that that they were HIV infected and then avoid treatment because of fear of being reported to the government when accessing the health care setting. In light of the treatment options that now exist, it is more important than ever that individuals be encouraged to seek HIV testing and early treatment. Any HIV surveillance system that is developed must also minimize individuals' concerns so that they are not discouraged from seeking early care and treatment. Mandated reporting by name would be the most likely system to increase individuals' reluctance to seek treatment.

- **Produce information that is actually utilized for planning and evaluation purposes in a manner that has the potential to improve the community's health.** As discussed in the goals section, it is absolutely critical that this surveillance data actually serve an important public health role in providing useful and timely information that is used to inform community planning and target and evaluate prevention efforts. If a surveillance system does not prove to be useful in this regard after its implementation, this data collection exercise should be stopped. Specifically, this data should clearly provide individuals living with HIV and those at risk for HIV infection with meaningful information to make decisions for themselves and should be used to ensure adequate availability of care and treatment services for people living with HIV.

In addition, surveillance data should provide useful and timely information that is accessible to the community (i.e., the data should be shared and widely distributed within the community). If the data is not timely or accessible, it will not provide sufficient benefit to people living with HIV to justify such a system.

It should also be noted that such data does not have to be 100% accurate and complete to provide useful information in discerning trends in the epidemic and planning for future service needs. Even with the most accurate data on AIDS cases, there is often a significant time lag between the AIDS diagnosis and the report to public health officials. Incomplete or imperfect data will certainly provide more information than we now have available, which would greatly help in determining broad trends in the epidemic. Accurate trend data is the most important information needed in order to conduct thoughtful planning.

- **Not violate confidentiality and/or civil rights and should include strong enforcement and penalties for disclosure of information.** Surveillance systems have the potential to be used for inappropriate purposes, such as utilizing lists to demonstrate knowledge of HIV status when attempts are made to punish individuals accused of exposing others to HIV infection. Although health departments have generally been extremely careful with this type of information, these departments could be compelled by legislative mandate or judicial order to surrender HIV case reports. For example, a recent United States Department of Health and Human Services proposal could lead to expanded law enforcement access to medical records. It is possible that this could include public health records, such as HIV case reports. In addition, although breaches by public health officials have been rare, they have occurred (most dramatically in Florida in 1996), and greatly increase community and individual concerns regarding confidentiality and privacy.

  Given the possibility of potential breaches in confidentiality, as well as the strong incentives of HMOs and other managed care entities and insurers to obtain such lists, it is critical that any system that is implemented make every effort to minimize—if not eliminate—the possibility of such disclosures. Any sort of named reporting of HIV infection clearly violates this principle and greatly increases the possibility for breaches and/or legislative mandate to disclose who is HIV infected. Finally, in order to minimize the potential for disclosure there should be extensive and enforceable penalties applied to anyone who tries to inappropriately access health department HIV case information or any health department personnel who disclose an individual's HIV status.

- **Not come at the expense of resources for treatment/services.** Although increased data could potentially be useful for planning and evaluation purposes, its benefit will be eliminated if resources for care or prevention services are re-directed to fund surveillance systems. Although surveillance data may be useful, it in no way supplants the need for adequate funding for HIV prevention and care services. In addition, the government must not use expenditures on HIV surveillance to indicate that something is being done to fight the epidemic. Counting cases is not equivalent to responding to the epidemic.

- **Respect individual choice with respect to name disclosure.** Any HIV surveillance system that is developed should provide individuals with the option not to have their names or other identifying information reported to the government. By ensuring this choice, the system will

reduce the potential for deterrence to testing and/or treatment as well as the likelihood of misuse of the information, thus minimizing the potential for negative consequences. This also helps to ensure that individuals living with HIV and those at risk for HIV infection have some control over the information that is available about them and minimizes the invasiveness of such surveillance systems. Given the mistrust of government in today's society, particularly among disenfranchised populations, individuals must be allowed to decide for themselves if they want identifying information provided to governmental entities.

Simply guaranteeing the availability of anonymous testing does not address this concern. If a names reporting system were instituted, individuals would have no control over the disclosure of their name when they accessed early treatment. The system must respect individuals' decisions about their names being reported or disclosed to public health authorities at not only the point of HIV testing, but also when individuals seek HIV care services.

Thus, mandatory names reporting should under no circumstances be required or encouraged. Other systems that do not rely on names, such as some type of unique identifier system that also meets the other criteria listed above, should be pursued if it is decided that HIV surveillance data is necessary and will be utilized in a manner that promotes the community's health.

The Foundation will remain opposed to any HIV surveillance system that does not meet the above criteria. Only by meeting these criteria will a system provide sufficient benefit to the community to outweigh any potential negative or damaging consequences.

Unique Identifier Reporting Must Be Examined as a Viable Alternative

The primary HIV surveillance system that is considered a potential alternative to names reporting is unique identifier reporting. Under such a system, an HIV-infected individual would not be reported by name to public health officials but rather by some form of a unique code that could not be traced back to the person. These types of systems use letters or numbers to represent data elements such as race, gender, and date of birth, which create a code with a high degree of uniqueness. Theoretically, this code is unique to the individual for whom it is developed (so that no one else is reported with the same identifier), and would be easily replicated every time the person is reported, thus ensuring an unduplicated count of HIV cases.

Unique identifier reporting has been seen as a potential compromise between those who strongly believe that better HIV data is needed and those who have strong public health and privacy concerns regarding HIV names reporting. Unfortunately, the experience with unique identifier reporting for HIV infection has been rather limited in the United States. Only two states—Maryland and Texas—have implemented such systems, and these have only been in place since 1994. Because these systems are the only ones that exist in the nation, they have been carefully scrutinized and compared to HIV names reporting systems in other states. Many have argued that the data regarding the effectiveness of these systems are not promising and have shown that these systems provide less complete information than that provided through names based reporting. This has led many to conclude that names reporting is the only viable HIV surveillance system available.

The Foundation disagrees with this conclusion. We do not believe that unique identifier reporting systems have been judged fairly in the national debate regarding HIV surveillance systems. Specifically:

- **Unique identifier systems have not been funded adequately.** While the CDC provides funding to states to implement names based reporting, relatively little financial support has been provided for unique identifier systems by either federal or state governments. Lack of resources has limited the ability to implement a system that is as effective as possible.

- **The evaluation of the current unique identifier systems has not adequately taken into account the fact that these systems are relatively new.** Both Texas and Maryland began implementing their systems in March of 1994, only a little over three years ago. The relative youth of these systems must be kept in mind when evaluating their effectiveness. These systems are bound to improve over time. To the extent that evaluations of these systems have shown potential problems, this information can and should be used to improve and build upon the existing systems and/or to assist in crafting new and better systems.

- **The standard used to judge unique identifier systems has been set unnecessarily high.** As noted above, absolutely complete and accurate data is not needed to analyze broad trends in the epidemic. Although the completeness of information provided by unique identifier reporting has not been as high as name-based reporting, it would certainly provide much more information than we currently have about emerging trends in the epidemic. This new data will significantly improve our ability to plan for upcoming health care and social service needs and appropriately target and evaluate prevention activities.

- **The fact that many states have implemented names-based reporting does not provide a legitimate rationale for opposing unique identifier reporting.** Some have argued that because 28 states currently require HIV names reporting, all other states should follow suit to ensure that there is a consistent reporting mechanism across the country. However, it is estimated that 75% of individuals living with HIV infection reside in states that do not require HIV case reporting by name. A national system must be designed to meet the legitimate public health needs of all states—including those with the largest percentage of people living with the disease.

The presumption that name-based reporting is the only effective system and the easiest to implement has led many to reject unique identifiers or other possible systems out-of-hand. The Foundation believes that if public health officials commit to providing proper attention and time to developing such a system, a reporting mechanism could be developed that would provide adequate and necessary surveillance data while greatly reducing the public health and privacy concerns related to name based reporting.

In conclusion, the Foundation certainly agrees that improved HIV surveillance data, if used appropriately, could benefit people living with HIV. However, collection of this data must be done in a manner that minimizes the potential for harm to these same individuals. We will continue to work to establish a system that meets both of these important goals.

October 8, 1997

Mr. Daniel Montoya
National AIDS Policy Office
808 17th Street, N.W., Suite 820
Washington, D.C. 20006

Dear Mr. Montoya,

Enclosed please find our paper on HIV Surveillance which I am sending at the request of your office.

It was our intention to use this document to peg down the parameters for discussion on surveillance. We do not favor names reporting but we are cognizant that the changes in the environment provoke discussion on improved methods of surveillance.

If you have any questions, I will be I Washington October 16-20 at the Hotel Club Quarters (202) 463-6400, or a message can be left at the AIDS Action Council. In the meantime, I am at (213) 993-1540.

Sincerely,

Mark S. Senak, J.D.
Director of Public Policy

1313 North Vine Street, Los Angeles, California 90028 • 213.993.1600

HIV Surveillance:

Recommendations for the New Era of the HIV Epidemic

September, 1997

APLA's Public Policy Department

ACKNOWLEDGMENTS

This project was developed and executed by Molly O'Shaughnessy, a graduate of Notre Dame University, under the direction of the Public Policy Department, as part of her summer internship at AIDS Project Los Angeles.

APLA would like to thank the many state AIDS Programs coordinators who responded to our inquiries for information in a timely manner.

INTRODUCTION

This document is a starting point to consider policy options to improve HIV surveillance efforts in the United States. It is not an endorsement of any one particular surveillance system. Rather, it identifies a set of essential conditions that must be met to ensure a viable and sound method for gathering better data about HIV infection is implemented in this country.

With aggressive drug therapies slowing the progression of HIV disease and resulting in sharply declining numbers of AIDS deaths in the United States, significant challenges in terms of prevention emerge. Clearly the need for information on the spread of HIV has never been greater, and the lag time inherent to using AIDS data to monitor HIV infection has become an insurmountable obstacle. In her statement at the July 14 AIDS Action forum, Dr. Helene Gayle, Director of HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention (CDC), pointed to the need for improved HIV surveillance as one of the most important challenges of the new era of the HIV epidemic.

The CDC is not alone in its increased attention to the need for better surveillance systems for HIV. A recently released draft position statement from the Council of State and Territorial Epidemiologists called AIDS surveillance "inadequate" for use in efforts to control the spread of HIV, and recommended that "all states and territories should implement confidential HIV infection reporting by name."[1] A widely discussed June, 1997 *Atlantic Monthly* article by Chandler Burr raised similar concerns. Burr argues that potentially successful tools of public health have been laid aside in the case of HIV, "largely to accommodate civil rights concerns," resulting in inadequate efforts to control the virus.[2] He uses the term "AIDS exceptionalism" to describe the manner in which AIDS has been excepted from traditional public health practices deployed against infectious diseases.

Many past attempts to implement HIV surveillance, like the attempt in Illinois to flush out HIV-infected health care workers, have been rooted in ignorance or hysteria. And the cries from the "AIDS exceptionalism" bandwagon, claiming that AIDS has been undeservedly exempted from traditional rules and methods of public health, seem to ignore the fact that the HIV epidemic has been approached differently because it *is* different. However, HIV reporting recommendations are

---

[1] Council of State and Territorial Epidemiologists. "National HIV Surveillance: Addition to the National Public Health Surveillance System." Draft Position Statement, 1997 #4.

[2] Chandler Burr, "The AIDS Exception: Privacy vs. Public Health," Atlantic Monthly, June 1997, p. 57-67.

increasingly founded in legitimate public health concerns. Considering the CDC's acknowledgment of the limitations of existing surveillance mechanisms, the fact that twenty-six states currently have laws requiring that cases of HIV infection be reported by name to state health departments, and the likely introduction of a bill to mandate HIV reporting in the California state legislature next year, the issues associated with HIV surveillance warrant examination.

BACKGROUND

Prior to the HIV epidemic, there existed a substantial body of legal and historical precedent for the disregard of civil or individual rights in favor of aggressive methods of controlling the spread of diseases which posed a threat to public health. These methods, from routine testing to mandatory reporting of infection to aggressive partner notification programs, were not suited to the AIDS epidemic at a time when no viable treatment options existed for those living with HIV. As a result, public health strategies for fighting the spread of HIV developed along less typical lines. The most important differences with regard to AIDS, of course, were the populations it affected, the stigma which arose around the disease, and the lack of available treatments. Maintaining the confidentiality of those living with AIDS was of paramount importance in the public health response to this epidemic.

In a *California Law Review* article tracing the development of legal protections of HIV-related information, Roger Doughty outlines four factors responsible for the emphasis on confidentiality in public health approaches to the AIDS epidemic. First, the populations most affected by AIDS, especially gay men, already suffered considerable stigmatization and discrimination and had reasons to mistrust government intentions toward them. Second, fear and ignorance of AIDS was spreading as fast as the disease was, fueling even more discrimination and adding to the confidentiality concerns of the infected. Third, disclosure of HIV-related information was not uncommon, and confirmed the fears of people with HIV. Finally, public health officials' need to gain the cooperation and trust of affected populations and individuals again made clear the need for confidentiality.[3]

Public health-centered reasoning, more than interest in the civil rights of those infected with HIV, led to the establishment of confidentiality protections of HIV-related information early in the epidemic. In order to encourage individuals to determine their HIV status, federal and state-funded anonymous HIV testing centers were created, and states receiving federal AIDS funding were required to protect the confidentiality of HIV and AIDS-related information. In response, many states also enacted stronger versions of their medical confidentiality laws specifically protecting such data and banned discrimination on the basis of HIV status.

Currently in the United States, all fifty states are required to report the names of patients diagnosed with AIDS to local and/or state health authorities, which forward demographic data to the CDC. However, there is considerable variation among the states with regard to HIV surveillance. Twenty-six states now have HIV-surveillance by name, and two more, Florida and New Mexico, are in the process of implementing name-based HIV surveillance. An additional three states report names of pediatric cases of HIV only. By comparison, Maryland and Texas report cases of HIV infection by unique identifier, using a number combining elements of the social security number and birth date with codes for race/ethnicity and gender. As many as thirteen more states and territories have some form of anonymous surveillance, in which testing centers report demographic information or simply numbers of people testing positive. Of the five states with the highest incidence of AIDS, Florida and New Jersey report HIV by name, and

[3] Roger Doughty, "The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic," California Law Review, 29 January 1994, p. 119-196.

Texas reports by unique identifier. California and New York, the states with by far the largest numbers of people living with AIDS, have no form of HIV surveillance.

Dramatic changes in the HIV epidemic are leading many to question current surveillance approaches to monitoring the AIDS epidemic in the United States. As treatment advances extend the lives of people with HIV, the limitations of AIDS surveillance will increasingly frustrate attempts to target funding for prevention, to determine needs for health care and social services, and so on. *More accurate incidence and prevalence data are needed in order to effectively fight the epidemic, and the information now available is becoming less useful.* HIV surveillance by name has been the practice in dozens of states for years with few major problems or leaks of information.

Despite these developments, two factors remain unchanged: individuals continue to fear unauthorized disclosure of their HIV status, and there remains the possibility of misuse of HIV-related data. Opponents of HIV surveillance argue that these concerns will deter people from getting tested, especially those in the highest-risk groups, as documented in studies which support these claims.[4] To mandate HIV surveillance at a time when early testing and treatment is needed more than ever may indeed be short-sighted public health policy.

In the middle of the debate are those who believe that the public health need for information can be fulfilled with less risk to individual confidentiality. This is the idea behind HIV surveillance by a system of "unique identifiers" instead of by names, a method already in use in Maryland and Texas. Critics of a unique identifier system argue that the complications of implementing and standardizing such systems are too great or that it is too soon to determine whether they will succeed.

The following document will outline the spectrum of proposed approaches to HIV surveillance, from the status quo to mandatory name reporting for all those who test HIV positive. In addition, the potential impacts of these proposals will be analyzed, and recommendations for the most prudent and effective policy with regard to HIV surveillance in this new era will be made.

[4] See bibliography: Johnson, Sy, and Jackson; Fehrs, et al.; Hirano et al.

POLICY PROPOSALS

The are currently four different proposed approaches to HIV surveillance and reporting:

- **Reporting of AIDS Only:** Some argue that the current arrangement of reporting AIDS diagnosis only should be maintained, pointing to studies which show that mandatory HIV surveillance will discourage testing. In addition, they claim that there is not enough evidence of the benefits of mandatory reporting to outweigh the risk of unauthorized disclosure and its consequences. Further study is necessary before HIV-infected people can be put at risk. All fifty states currently report AIDS.

- **Anonymous HIV Reporting:** Others think that all public and private testing centers and health care providers should be required to report positive test results using general demographic data and exposure category. Reporting by demographic data alone cannot adjust for potential duplication. In order to ensure privacy, no name or unique identifier would be required. As many as 13 states have some form of anonymous reporting for HIV (although it may only be required in publicly funded testing centers).

- **HIV Reporting by Unique Identifier:** Proponents of a unique identifier system suggest that persons testing positive for HIV should be reported to public health departments, using some form of unique identifier other than name to ensure confidentiality without duplication of data. Two states, Maryland and Texas, currently employ unique identifier systems of HIV surveillance.

- **HIV Reporting by Name:** Others argue that in order to improve surveillance of HIV, all public and private testing centers and health care providers should be required to report every positive test for antibodies to HIV. They support the use of names in order to prevent duplication, and think that HIV related information should remain confidential and heavily safeguarded by public health institutions. This approach allows for partner notification, a separate policy issue which is often blended with names reporting. Among supporters of this approach there is debate as to whether the option of anonymous testing should remain available. Twenty-eight states currently have laws requiring named reporting of adults testing positive for HIV (see following table).

STATES WITH HIV REPORTING BY NAME OR UNIQUE IDENTIFIER

STATE	Date Implemented	METHOD		Anonymous Testing Available?	
		Name	Unique ID	YES	NO
Alabama	Jan-88	X			X
Arizona	Jan-87	X		X	
Arkansas	Jul-89	X		X	
Colorado	Nov-85	X		X	
Connecticut	Jul-92	*		X	
Florida	Jul-97	**		X	
Idaho	Jun-86	X			X
Indiana	Jul-88	X		X	
Louisiana	Feb-93	X		X	
Maryland	Jun-94		X	X	
Michigan	Apr-92	X		X	
Minnesota	Oct-85	X		X	
Mississippi	Aug-88	X			X
Missouri	Oct-87	X		X	
Nebraska	Sep-95	X		X	
Nevada	Feb-92	X			X
New Jersey	Jan-92	X		X	
New Mexico	Jan-98	**		X	
North Carolina	Feb-90	X			X
North Dakota	Jan-88	X			X
Ohio	Jun-90	X		X	
Oklahoma	Jun-88	X		X	
Oregon	Sep-88	*		X	
South Carolina	Jan-92	X		X	
South Dakota	Feb-94	X			X
Tennessee	Apr-89	X			X
Texas	Feb-94	*	X	X	
Utah	Apr-89	X		X	
Virginia	Jul-89	X		X	
West Virginia	Jan-89	X		X	
Wisconsin	Nov-85	X		X	
Wyoming	Jun-89	X		X	

*Connecticut, Oregon, and Texas require reporting of pediatric HIV infection by name.
** Florida and New Mexico are at the implementation stage noted by date.

ANALYSIS

Public policy, especially as it relates to public health, deals constantly in the tension between individual rights and collective interests. The potential conflict between the need to track infectious diseases and the need to protect the privacy of individuals' health information is one example. Because of the unique nature of the AIDS epidemic, policy in that area has traditionally protected individual privacy in order to serve the public health interest in linking at-risk populations to HIV testing and health care.

Today, the balance between the individual need for privacy and the public health need for information relating to HIV has shifted. The statistical method used to compensate for the lack of HIV information (by extrapolating from AIDS data) has always been handicapped by a lag in the data because of the period it takes for people infected with HIV to develop AIDS. With new treatments extending the lives of people with HIV and slowing the progression to AIDS, this gap in data will continue to grow, resulting in AIDS data becoming even less useful for making decisions in the battle against HIV. This is problematic as the amount of public funding for states and local governments for HIV services is based on the number of reported cases of AIDS. As a result, funding jurisdictions will not receive adequate resources to meet the true need in their respective areas. While the need for individual trust in the security of HIV-related information remains important for early testing and treatment, the need for improved surveillance methods for HIV has grown disproportionately. *The data currently used in nearly every policy decision regarding the HIV epidemic, in targeting at-risk populations for prevention efforts and in appropriating billions of state and federal dollars each year to fight this epidemic is no longer adequate, due to recent advances in treatment.*

On the other side of this shifting equilibrium are the legal confidentiality protections of health-related and HIV-related information, which have been continually strengthened over the years of the epidemic. Laws have been created to protect HIV information, to establish penalties for unauthorized disclosure, and to prohibit many forms of anti-HIV discrimination. These have provided a minimum standard for ensuring confidentiality and a means of legal recourse for those infected with HIV to address significant breeches. However, it is not clear that existing statutes are sufficient to serve as deterrents to discriminatory actions or as an incentive to reduce the stigma surrounding HIV. At least thirty-six states have enacted specific privacy protections for HIV-related information, while the rest protect HIV under existing statutes designed for other health information. Forty-five states have some type of penalty for unauthorized disclosure of HIV-related information, and thirty-three states allow for criminal punishment. Although some forms of discrimination based on HIV status are not illegal (e.g. with regard to insurance), since 1990 the Americans with Disabilities Act (ADA) has outlawed many types of discrimination against people with HIV or AIDS, such as in housing and employment.[5] However, a recent case in Florida demonstrates how ineffective confidentiality provisions can be. An employee of the Florida Department of Health Rehabilitative Services was caught in a gay bar showing a

[5] Lawrence Gostin, Zita Lassarini, and Kathleen Flaherty, "Legislative Survey of State Confidentiality Laws, with Specific Emphasis on HIV and Immunization," Report to CDC, CSTE, and Task Force for Child Survival and Development, 2 July 1996, p. 62-63, 77, 90.

confidential list of named individuals who were diagnosed with AIDS and reported to health authorities in that local jurisdiction.

The goals of protecting individual privacy and gathering information for public health purposes are not mutually exclusive; it is both possible and practical to enhance surveillance of HIV while continuing to protect individual confidentiality. No surveillance system will be perfect in either respect. However, the quality of data on HIV cannot get much worse, and the risk of confidentiality violations already exist in many arenas. Pharmacy records of HIV-related prescriptions and medical records of opportunistic infections related to HIV are examples of data which may leave individuals exposed to breach of confidentiality under the existing system. Recommendations for improved confidentiality follow the analysis of current proposals. The goal of this analysis is to evaluate the ability of each proposed system to acquire better data on HIV without exposing individuals to unreasonable risks.

With this goal in mind, the following is a direct examination of the proposed approaches to HIV surveillance:

- **Reporting of AIDS Only:** The only argument for maintaining the status quo is one of caution. This argument claims that other approaches have not been tested enough, and that to increase surveillance of HIV is to expose people living with HIV to unnecessary risks of disclosure of their status. In fact, at this crucial point in the epidemic, it is much more dangerous to continue to use faulty data in policy decisions which affect every aspect of the fight against HIV. In attempting to protect those with HIV, this approach would eventually cripple the many programs which serve them.

- **Anonymous HIV Reporting:** While as many as thirteen states have some form of anonymous surveillance, the data acquired in such systems is of questionable use, due to the potential for duplication of data. In some states, only publicly funded testing centers report demographic data on people who test positive. Private labs or individual health care providers may not be required to report positive test results, or enforcement of requirements may be lacking. In other states, testing centers and providers are *permitted* instead of *required* to report cases of HIV infection, often for purposes of partner notification. States which report HIV without using names certainly run less risk of violating individual privacy. However, there are no means to account for duplication of positive tests in anonymous systems, and the result is skewed data which may not be much more useful than AIDS data alone. In light of the goal of acquiring better information on the spread of HIV, a system of anonymous surveillance would simply be inadequate.

- **HIV Reporting by Unique Identifier:** In theory, a system of reporting by some unique identifier other than name is quite attractive. To avoid duplication without releasing names to the health department, testing centers or health care providers report cases of HIV using a number or code unique to each person. One format commonly proposed for this identifier includes part of the social security number, the birth date, and codes for race and gender. A successful system of unique identifiers could collect accurate data on HIV while protecting confidentiality of infected individuals.

The most common concern of those who question the viability of unique identifiers is the practical difficulty of effectively implementing and enforcing such a system. Maryland and Texas, the only two states where HIV is reported by unique identifier, have both experienced considerable problems in obtaining accurate data, mainly because of widespread noncompliance and incompleteness on the part of the centers or providers reporting the cases. One Texas health official estimated that as many as 70% of HIV infection reports received by the state health department are incomplete and are never entered into the state's database. Neither state is obtaining data which could be considered accurate. For now, critics of unique identifiers who claim it is too impractical and cumbersome to implement have yet to be proven wrong. Clearly, a unique identifier system merits additional study and consideration before implementation in a jurisdiction like California. This analysis should focus on identifying and correcting the deficiencies in such a system, to avoid replicating the problems with incomplete results and faulty data both Maryland and Texas are experiencing.

- **HIV Reporting by Name:** When New Mexico completes implementation, a total of twenty-eight states will require reporting of cases of HIV infection to state health departments, using names in order to prevent duplication and to allow for tracking of individual cases.[6] Names are held as confidential by the health departments and protected by a variety of laws and policies prohibiting unauthorized disclosure. Supporters of name reporting systems claim that the data is extremely useful in HIV-related policy making, funding, targeting of prevention efforts, and so on.

  The most important argument against named HIV surveillance is that confidentiality concerns will deter people from being tested, especially those in groups at high risk for infection. Many advocates of name reporting support the continued availability of anonymous testing for those who would not otherwise test, as is the case in at least twenty of the states with name reporting. Accessible, publicly funded anonymous testing centers will lead to some skewing in data, but will ensure that no individual is prevented from testing because of fears about confidentiality. Another concern of critics of named reporting is the risk of disclosure presented for those who test positive at confidential sites and whose names are held by health departments. While no system can assure perfect confidentiality, this issue must be addressed, by reducing fears about disclosure and by increasing legal confidentiality protections, if HIV reporting by name is to be successful.

[6] In addition, Connecticut, Oregon, and Texas require named reporting only for children infected with HIV.

RECOMMENDATIONS

Among those whose task is to influence policy rather than to make it, there is a tendency to point out the flaws in every proposal rather than to suggest solutions. This tendency to act as a cautionary or advocating voice is often helpful and can affect policy in positive ways. In the case of HIV surveillance, the opposite will be true. The effect of lamenting the current situation while criticizing every proposed alternative will be either to paralyze policy in a time when decisiveness and flexibility is so important or to be completely eliminated from any decision process. It is more productive for the HIV-impacted community to work directly on developing solutions and strategies that meet the demands of the changed environment of the HIV epidemic.

In light of this goal, rejecting all forms of HIV surveillance in the name of protecting the interests of people with HIV would be counterproductive. Instead of fighting the epidemic with all available tools of public health, this approach will in fact result in programs for treatment and services which are ill-suited to the needs of people living with HIV.

A public health commitment to fighting HIV requires a commitment to better information, and the most viable and sound method for gathering that information is a system of HIV surveillance *which meets the following essential conditions:*

- ***Anonymous Testing must remain accessible and available*** to all of those who choose it, in California and in all fifty states. No person should be prevented from accessing testing because of concerns about privacy.

- ***HIV-impacted communities must be brought into any surveillance planning process*** in order to ensure the trust and cooperation of those affected by HIV disease, and to lend legitimacy and validity to the new system. A group made up of representatives of communities affected by HIV, as well as health care providers, public health experts, and ethicists must participate in every step of the process. This includes planning, development, and implementation as well as assessment of and adjustment to the HIV surveillance system. With the help of HIV-impacted communities, the planning process must be accompanied by education and the release of straightforward information in order to reduce fears and misconceptions about HIV surveillance.

- ***Access to Treatment and Epidemiological Studies must be guaranteed upon request to all those who test HIV-positive.*** The recently released *Report of the NIH Panel to Define Principles of Therapy of HIV Infection* outlines the scientific basis for a new standard of treatment protocol, strongly suggesting that the best way to treat HIV infection is to treat early and aggressively. Based upon these recommendations, it is clear that any successful strategy for HIV surveillance must include guaranteed access to treatment and epidemiological studies, as requested.

- ***Legal confidentiality and anti-discrimination protections must be reviewed and reinforced*** in order to ensure the security of HIV-related information and secure a consistent level of protection for people with HIV against discriminatory practices. While confidentiality laws

exist, gaps in protection and variations within and between states allow significant room for improvement. Review by legal experts, along with the participation of communities impacted by HIV, should undertake to strengthen protections of individual privacy. Increased protections will serve the confidentiality interests of individuals being tested for HIV, and will result in better surveillance data by increasing the level of individual trust in the testing system. Several different areas of confidentiality protections must be examined, especially the following:

The safeguarding of all "HIV-related information:" This includes not only antibody test results but all other direct and indirect indicators of HIV, from viral load test results to records of common opportunistic infections to prescription records for HIV medications.

Variation by who holds the data: Another area of concern is whether the standards and legal duty to protect confidentiality should vary among public health departments, health care providers, and other institutions possessing sensitive health information, such as employers and schools.

Practical implementation: The specific steps which organizations are required to take in protecting confidentiality, including limiting internal access to data, developing clear confidentiality policies, training employees with regard to privacy protections, and others should also be reviewed.

Sufficient penalties: Both civil and criminal penalties for negligent or purposeful unauthorized disclosure of HIV-related information should be reexamined to ensure that they are adequate to deter such disclosures and to provide sufficient legal recourse for the victims of such disclosures.

More uniform standards among states: The variation in protections of health care information from state to state has become dangerous in the age of multi-state health care organizations and an increasingly mobile population. On the other hand, a federally mandated standard for health and HIV-related confidentiality protections would be politically unlikely, would restrict innovation and experimentation in individual states, and might even lower standards in some states. One approach which would establish uniform standards while maintaining states' flexibility would be a set of initiatives in state legislatures based on a set of model confidentiality laws, designed either to protect all health care information or data related to HIV.[7]

- ***Education aimed at reducing the stigma surrounding HIV and AIDS*** must continue and be given increased attention in order to create a supportive environment for testing. A continued campaign against fear and ignorance of HIV is a necessary companion to prevention efforts and to confidentiality and anti-discrimination laws. Clear messages that support is available for those who test positive for HIV are essential in any attempt to convince individuals to find out their HIV status. Community-based, culturally sensitive adjuncts to prevention campaigns

[7] Gostin et.al., p. 159-162.

have the potential to further improve surveillance data by reducing the fear and stigma surrounding HIV which can lead to avoidance of testing.

- ***New monies must be appropriated to implement any system of HIV surveillance.*** Either federal or state money must be made available to implement any successful HIV surveillance effort, and must not be diverted from other current services that are crucial to stemming the advance of the epidemic.

- ***De-link the issue of partner notification,*** which is often erroneously connected to the issue of HIV surveillance. HIV surveillance should not have any effect on voluntary partner notification programs in which the index or referring partner is not named. While the success of many notification programs may merit their expansion, the issue should not be connected to the expansion of surveillance.

CONCLUSION

As advances in treatment have led to a decline in AIDS deaths and renewed hope for people living with HIV, so have they led to a reexamination of the epidemic and the means employed in fighting it. One result of these treatment advances has been an increased awareness of the discontinuity inherent in using data on people with AIDS to make decisions in fighting the spread of HIV and in serving people with HIV. Billions of dollars of prevention, treatment, and service programs are being funded and administered using data which is not suited for the purpose. While calls to increase HIV surveillance are often founded in fear and ignorance of the epidemic, recent proposals have emerged that are more rational and based on the need for improved information on the HIV epidemic.

The capacity to obtain this improved data on HIV is within reach, but any increase in HIV surveillance involves a risk to individual privacy. However, it is important that this risk be put in proper perspective. The infamous disclosure of names from a confidential health department AIDS database in St. Petersburg, Florida occurred under the same AIDS surveillance system now in place in all fifty US states. At the same time, few breaches of confidentiality have occurred in states with named HIV reporting. If a program of HIV surveillance by name is implemented carefully and with full participation by the communities affected by HIV, better information on the spread of the epidemic can be obtained without unreasonable risks to individual confidentiality.

HIV surveillance is by no means an end in itself; it is merely a means to obtain accurate information which will allow the battle against HIV to be fought in the most effective manner. By implementing a system which provides better data on HIV, we will be able to work for increased access to proper treatment and services for all people with HIV, as well as more effective prevention. However, none of these efforts will be worthwhile without continued public and private commitment to fighting HIV.

References

Burr, Chandler. "The AIDS Exception: Privacy vs. Public Health." Atlantic Monthly, June 1997, p. 57-67.

Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1996; 8(no. 2).

Council of State and Territorial Epidemiologists. "National HIV Surveillance: Addition to the National Public Health Surveillance System." Draft Position Statement, 1997 #4.

Doughty, Roger. "The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic." California Law Review, 29 January 1994.

Fehrs, L.J., D. Fleming, R. Foster et al. "Trial of anonymous versus confidential human immunodeficiency testing." Lancet, August 1988, 379-382.

Forbes, Anna. "Naming Names: Mandatory Name-based HIV Reporting: Impact and Alternatives." AIDS Policy and Law, May 1996.

Gostin, Lawrence, Zita Lassarini, and Kathleen Flaherty. "Legislative Survey of State Confidentiality Laws, with Specific Emphasis on HIV and Immunization." Report to CDC, CSTE, and Task Force for Child Survival and Development, 2 July 1996.

Hirano, D., G.A. Gellert, K. Fleming et al. "The impact of availability on demand in Arizona." American Journal of Public Health, December 1994, 20008-20010.

Johnson, H.D., F.S. Sy, K.L. Jackson. "The impact of mandatory reporting of HIV seropositive persons in South Carolina." Presented at the IV International Conference on AIDS, Stockholm, Sweden, 1988.

DRAFT

MOVING FROM AIDS TO HIV SURVEILLANCE: CREATING AN EFFECTIVE PUBLIC HEALTH RESPONSE TO THE CHANGING EPIDEMIC

October 1997

Introduction

Since the beginning of the AIDS epidemic, public health officials have used epidemiological tools to monitor the extent and effect of the disease. One of these tools is an AIDS surveillance system, under which AIDS cases are reported by name to local and state health officials, who remove patient identifying information and forward coded data to the Centers for Disease Control and Prevention (CDC). The CDC then develops a national profile of the AIDS epidemic, which is used, among other things, to report trends in the epidemic, allocate resources, and help target prevention efforts. All 50 states are required to report AIDS cases to the CDC. Currently, there is no comparable federal requirement for states to report cases of HIV infection which have not yet progressed medically to the point of an AIDS diagnosis.

This paper will discuss how recent developments in the AIDS epidemic support the conclusion that an HIV surveillance system can now better meet public health needs and goals than an AIDS surveillance system. It will examine what an HIV surveillance system should accomplish, and how it could be structured. It will also explain two different approaches to reporting HIV cases to public health departments–name reporting systems and unique identifier systems– and explore how the characteristics of each system affect its ability to achieve public health goals. It will discuss why, under current conditions, we believe that the negative aspects of HIV name reporting outweigh its benefits, and therefore oppose this approach. Partner notification, a separate policy issue often discussed in connection with HIV surveillance, will not be addressed in detail in this paper.

Historic Reasons for Opposing HIV Surveillance

In the past, many groups, including AIDS Action, have opposed reporting cases of HIV infection. There have been several reasons for this opposition.

First, because AIDS initially appeared in populations which have traditionally been discriminated against (gay men and injection drug users), and because of the stigma which quickly surrounded the disease, there was concern about reporting HIV cases and suspicion about what would be done with the information collected. This concern was justified, in light of the fact that few confidentiality protections existed in law, and that proposed policies were often driven by fear and misunderstanding. Historically, proposals for HIV surveillance almost always called for mandatory name reporting.

Second, there was no cure or even effective treatment to offer those infected with HIV and no medical way to make an infected person uninfectious, reasons given under traditional public health practice for reporting cases of a disease. The limited treatments available were for people whose HIV disease had progressed to an AIDS diagnosis–people with severely suppressed immune systems, a low number of "T-cells," and opportunistic infections, such as pneumocystis carinii pneumonia (PCP).

Finally, there was fear that reporting HIV cases would drive people away from testing and the health care system generally–especially those who might be likely to test positive for HIV–and therefore would undermine public health efforts. In short, the harm that could potentially have come from HIV surveillance outweighed the benefits that it could provide.

States' Responses

Despite these concerns and the fact that the CDC does not currently mandate HIV surveillance, 30 states have chosen to require reporting of cases of HIV infection, with 28 reporting the names of HIV-infected individuals to local and/or state public health officials, and two states (Maryland and Texas) using unique identifier codes rather than names (see Tables 1and 1A). Three states–Connecticut, Oregon and Texas–require reporting the names of pediatric HIV cases only. Some other states use anonymous HIV surveillance, reporting general demographic and exposure category data only. While anonymous surveillance can give some indication of trends in the epidemic, it cannot account for duplication (people diagnosed HIV at more than one site) and therefore, the accuracy of the data provided cannot be substantiated.

Many of the states and territories with a higher incidence of HIV and AIDS, such as California, New York, Puerto Rico, Pennsylvania and Massachusetts, do not require HIV surveillance. Others, such as Florida, New Jersey and Louisiana, report HIV cases by name.

Among the 28 states reporting HIV cases by name, 20 maintain the option of anonymous HIV testing (in which patients' names are not used). Eight name reporting states (Alabama, Idaho, Mississippi, Nevada, North Carolina, North Dakota, South Dakota, and Tennessee) do not have anonymous testing available.[1]

The Changing Epidemic: Increased Calls for HIV Surveillance

Over the past few months, there has been increasing debate over whether cases of HIV infection should be surveilled and reported. This debate has been prompted by the CDC, which has indicated its support of states establishing HIV surveillance systems and reporting HIV surveillance data to the CDC. Unlike legislation requiring a national list of names of HIV infected individuals, such as Representative Tom Coburn's (R-OK) HIV Prevention Act of 1997, discussions to date center around providing coded surveillance data to the CDC.

Also contributing to the widespread discussion about HIV surveillance are certain developments in the epidemic. One development is the introduction of combination drug therapies with protease inhibitors, which have dramatically improved the health and prolonged the lives of many people with HIV. According to the CDC, AIDS deaths declined for the first time in 1996 (a decrease of 23% compared to 1995), partly due to improved treatments.[2] In response to the

---

[1] AIDS Project Los Angeles, *HIV Surveillance: Proposals for the New Era of the HIV Epidemic*, Summer 1997.

[2] Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report*, September 19, 1997, Vol. 46, No. 37.

promise of these therapies and to clinical evidence which suggests that they are more effective when started early in the course of HIV disease, treatment guidelines now call for early and aggressive intervention. There are now more compelling reasons to encourage testing and provide links to treatment than when there were few effective treatment options. By providing information on the number and demographics of people testing HIV positive, HIV surveillance can help with the allocation of resources for early intervention and treatment.

Another development due to treatment advances, such as combination drug therapies and improved treatments for opportunistic infections, is that people with HIV infection are generally living longer and progressing to an AIDS diagnosis much more slowly than in past years. Therefore, conducting surveillance of AIDS cases only does not provide an accurate view of the extent of the epidemic, since those with HIV infection (but not AIDS) will not be represented.

Finally, the demographics of the epidemic have shifted rapidly over the past few years, a shift which may not be captured by AIDS surveillance. More new HIV infections are occurring in women, heterosexuals, injection drug users, and people of color. AIDS surveillance alone will not give a timely and complete indication of trends in HIV infection, and thus is less useful for targeting prevention efforts and identifying needs for care and treatment.

HIV surveillance can allow us to develop a more accurate picture of the current epidemic and craft a more finely-tuned response.[3] As the CDC states, HIV surveillance can "provide a more timely measure of emerging patterns of HIV transmission, a more complete estimate of the number of persons with HIV infection and disease, and a better mechanism to evaluate access to HIV testing and medical and prevention services than AIDS surveillance alone."[4]

The CDC Advisory Committee on the Prevention of HIV infection has specified five goals for public health surveillance of HIV and AIDS. The CDC has articulated that an HIV surveillance system could improve our ability to meet the following goals:

- target primary and secondary prevention
- evaluate the efficacy of prevention activities
- determine eligibility for federal, state, and local health resources for services for HIV-infected individuals
- project future resources needed for care and prevention efforts
- educate the public about the scope and impact of the epidemic[5]

---

[3] It is important to note, however, that introduction of HIV surveillance does not automatically trigger a reallocation of resources designated for care and prevention. In fact, any such reallocation would require, at minimum, statutory changes in the Ryan White CARE Act. Prevention planning committees have discretion in allocating prevention funds, notwithstanding surveillance trends. If HIV surveillance were to be implemented, there would not be an immediate change in allocation of resources.

[4] *Id.*

[5] Council of State and Territorial Epidemiologists and Centers for Disease Control and Prevention, *Consultation on the Future of HIV/AIDS Surveillance*, The Carter Center, May 21-22, 1997.

By giving us more of the information that is relevant, HIV surveillance can help us better understand where the epidemic is going. If planned and implemented carefully and thoughtfully, HIV surveillance can be a valuable tool in fighting HIV and AIDS.

Moving from AIDS to HIV Surveillance

Because of changes in the epidemic, AIDS Action believes that AIDS surveillance can no longer provide as timely, complete, representative, and accurate a reflection of the epidemic as we need. We believe that HIV surveillance could be an important tool in the fight against AIDS. **AIDS Action supports the creation of an HIV surveillance system, provided that such a system supports public health goals, such as protecting the confidentiality of those living with HIV and not deterring people from seeking HIV testing.**

Creating an Effective HIV Surveillance System

Background

Once the need for establishing an HIV surveillance system as part of public health efforts to fight the AIDS epidemic is acknowledged, the questions become how such a system should be structured and implemented.

There are many potential ways to set up an HIV surveillance system, all of which involve striking a balance between sometimes competing concerns. Such competing concerns include balancing a desire for ease of administration with the need to protect privacy, or using standardized methods versus maintaining flexibility to meet local needs. Ultimately, all agree that an effective surveillance system must support our public health goals.

Important characteristics for a surveillance system that supports our public health goals include:

- the system must be simple to administer and provide data which is timely, reliable, comprehensive, representative and does not duplicate reports
- the system must include a standard set of data elements, so that a national profile of the epidemic can be developed, and include the use of methods which can give rates of disease and estimate trends of risk behavior in sub-populations (e.g., injection drug users, heterosexuals)
- the system must have the flexibility to be adapted to local needs
- the system must maintain confidentiality and privacy
- the system must not deter people from HIV testing and medical intervention

Two Types of HIV Reporting

While there is generally agreement about the public health goals of a surveillance program, debate is ongoing as to which HIV reporting system can best accomplish these goals. The two

main systems of HIV reporting currently in use are name reporting and unique identifier reporting.

Under a name reporting system, the names of persons infected with HIV, along with their demographic and exposure category information, are sent to local and/or state public health officials. Coded information is then forwarded to the CDC.

A unique identifier reporting system creates a distinct code number for each person testing HIV positive, and that code number, rather than the individual's name, is reported to public health authorities, with the accompanying data. A unique identifier system incorporates data elements specific to that person. For example, Maryland and Texas, the only two states currently using a unique identifier system, generate a unique identifier by taking the last four digits of a person's Social Security number combined with the date of birth and codes for gender and race/ethnicity.[6]

Both name reporting and unique identifier reporting have the potential to meet the goals of public health surveillance. Each system has particular characteristics which have repercussions for how well the system meets these goals. In weighing the characteristics of each method of reporting, it is important to consider all of these potential implications.

Name Reporting

Key Characteristics

- simpler to administer
- likelihood of provider compliance with reporting (due to ease of administration)
- likelihood of timely, reliable data
- gives the ability to provide follow-up and referrals to care and treatment
- can provide data to help in decisionmaking about equitable allocation of resources and in making projections about resources needed in future for care and prevention
- enhances ability to target and evaluate prevention efforts
- provides ability to conduct partner notification
- greater risk of breach of confidentiality of HIV infected persons
- increased likelihood of deterring people from HIV testing, particularly people with high risk behaviors

Pros

Reporting HIV cases by name is an easy method, in terms of administrative effort, given that such a system could be set up in the same way as the system currently used for AIDS reporting. Because this method involves a minimum of effort on the part of health care providers and laboratories, who are already familiar with the process, provider compliance with the system is likely to be high and the data which is collected is likely to be complete. More complete data means a better ability to target and evaluate prevention efforts, and to allocate present and future resources.

---

[6] The gender and race/ethnicity codes come from the codes used by the CDC for AIDS case reporting.

A name reporting system is less expensive to create and implement than other types of surveillance systems. Name reporting also minimizes the chance of counting someone more than once if that person receives HIV-related services at multiple locations.

Having the names of HIV infected individuals makes it easier to provide links to treatment and services. For example, if the Medicaid program were expanded to provide coverage for low-income individuals in early stages of HIV infection, a name reporting system would enable health officials to contact individuals to inform them of this benefit and enroll them in the program. Additionally, name reporting is compatible with efforts to conduct partner notification and contact tracing should they be determined to be desired public health goals.

Cons

Perhaps the biggest problem with name reporting of HIV cases is the potential for breaches of confidentiality. Such a method would create name registries of HIV infected individuals – registries which, if disclosed, could cause profound harm to those whose privacy was violated. These are registries which could be in existence for decades, and which would list people who are not necessarily ill or disabled. The incident earlier this year in Pinellas County, Florida, in which names of people with AIDS were removed from the health department by an employee illustrates the potential risk of maintaining lists of names.

Both the CDC and the Council of State and Territorial Epidemiologists have recognized the importance of confidentiality protections for people with HIV, and have acknowledged the seriousness of a potential breach of that confidentiality. In fact, the organizations have commented that the confidentiality concerns regarding an HIV surveillance system are even greater than those for an AIDS surveillance system, due to "the fact that many persons with HIV infection are not ill and/or not receiving health care, that HIV surveillance reports must be maintained for longer periods of time...and that the negative consequences of unauthorized disclosure of HIV infection status are potentially greater than for AIDS."[7]

At the present time, we do not have laws in all states which safeguard the confidentiality of HIV-related information and which provide for sanctions strong enough to deter breaches in confidentiality. Without stronger privacy and confidentiality protection laws which apply to all states, the risks in creating and maintaining name lists of HIV infected persons are too great to justify such a system.

In fact, a name reporting system would force many states to weaken their existing confidentiality protections, or to reopen debate with those who oppose strong HIV confidentiality measures. For example, Massachusetts law requires written informed consent from a person before that person's HIV status may be disclosed.[8] A name reporting system would violate this law. Thus

---

[7] Council of State and Territorial Epidemiologists and Centers for Disease Control and Prevention, *Consultation on the Future of HIV/AIDS Surveillance*, The Carter Center, May 21-22, 1997.

[8] Massachusetts General Laws, Chapter 111, Section 70F.

far, proposals for name reporting have not included provisions to strengthen confidentiality protection laws.

Some recent federal appellate court decisions have found that the protections of the Americans with Disabilities Act (ADA) do not extend to people with asymptomatic HIV infection.[9] While this issue has not been conclusively decided across the country, these court decisions take away protection from discrimination from many HIV infected people. In light of these decisions, it is even more misguided to create registries of names of people who may be discriminated against if the registry is disclosed, and who cannot be assured of recourse under the ADA.

Another problem with name reporting, closely related to the issue of confidentiality, is that it discourages people from seeking HIV testing. Individuals fear misuse of their private information and worry that their confidentiality will be breached. Several studies have had findings supporting this contention.

One 1996 study conducted at anonymous and confidential test sites in Los Angeles found that 86 percent of respondents would not seek testing if the names of those testing HIV positive were reported to a government health agency.[10] Respondents who perceived themselves to be at increased risk for HIV infection were even more likely to avoid testing if a name reporting system existed. When asked what their response would be if names of HIV infected individuals were reported at the time of seeking treatment (as opposed to at the time of testing), nearly 23 percent said that they would wait until they became ill to seek medical treatment. The study's authors concluded that name reporting would deter testing and "would undermine the primary objective of early intervention–to prolong the health and productivity of HIV infected people."

The Multistate Evaluation of Surveillance of HIV (MESH) Project, a nine-state survey funded by the CDC, found that 20 percent of people surveyed with high risk behaviors for HIV listed the fear of name reporting as a reason for avoiding HIV testing.[11] A study of people seeking HIV testing at anonymous test sites found that more than 60 percent of respondents would not be tested for HIV if positive test results had to be reported to health officials.[12] Another survey reported that 76.8 percent of the study group cited not wanting their names on a government list as a reason for not having an HIV test, the single most important reason given.[13]

---

[9] See, e.g., *Ennis v. National Association of Business and Educational Radio, Inc.*, 53 F.3d 55 (4th Cir. 1995); *Runnebaum v. Nationsbank of Maryland, N.A.*, 1997 WL 465301 (4th Cir. (Md.))

[10] G. Reed, et. al., "The Impact of Mandatory Name Reporting on HIV Testing and Treatment–A Study from Los Angeles County," Poster Presentation for the XI International Conference on AIDS, July, 1996.

[11] A. Forbes, "Myths and Facts About HIV Case Reporting by Name Versus by Unique Identifier," September, 1997.

[12] S. Kegeles, et. al., "Many People who Seek Anonymous HIV-Antibody Testing Would Avoid It Under Other Circumstances," *AIDS*, 1990: 4:585-588.

[13] T. Meyers, et. al., "Factors Affecting Gay and Bisexual Men's Decisions and Intentions to Seek HIV Testing," *American Journal of Public Health*, May 1993, Vol. 83, No. 5.

If name reporting drives people, particularly those with high risk behaviors, away from testing, it undermines a primary public health objective and severely hampers efforts to prevent HIV transmission. The knowledge of one's HIV status and the education about HIV transmission methods received with testing and counseling are critical to reducing risky behavior.

In addition, deterring people from testing means that name reporting cannot provide the most accurate, comprehensive, representative, complete, and timely data possible about the course of the epidemic.

While name reporting could potentially assist in ensuring that those who are HIV positive receive care and treatment, at the present time, name reporting of HIV in no way guarantees access to medical care and new drug treatments. In 1996, the federally-funded AIDS Drug Assistance Program (ADAP) provided medications to between 14 percent and 28 percent of ADAP-eligible individuals.[14] There are simply not enough resources currently available to provide treatment for all who need it. Proposals for national mandatory name reporting have thus far not included provisions for linking people testing HIV positive to medical care and expanding treatment access. There is no evidence that states which require name reporting have enhanced access to care for their HIV-infected population. In fact, some states with HIV name reporting systems have Medicaid and ADAP programs which are insufficient to meet current needs for care and medication coverage.

Finally, supporters of name reporting claim that it facilitates the process of partner notification. But the name of the person testing HIV positive (the "source patient") is not what is important in partner notification, rather, it is the names of the sexual or needle-sharing partners of the source patient. In many partner notification programs, the public health official doing the notification does not even know the source patient's name. A recent CDC-funded, nine state survey found that people testing for HIV at anonymous test sites (where names are not used at all) provided the same number of partner names as those testing at confidential sites (where names are collected).[15] In fact, source patients may be *more* reluctant to provide partner names if they believe that their identity may be disclosed to their partners.

States which still choose to use name reporting as an HIV surveillance tool despite these disadvantages should, at a minimum, maintain the option of anonymous testing for those individuals who will not test for HIV without assurance of their anonymity. Such states also must enact privacy protections which provide for penalties severe enough to underscore the importance of confidentiality and deter breaches.

---

[14] A. Forbes, "Myths and Facts About HIV Case Reporting by Name Versus by Unique Identifier," September, 1997.

[15] *Id.*

Unique Identifier Reporting

Key Characteristics

- better maintains confidentiality
- reminds providers, public health officials, and public of seriousness of information and increases vigilance around protecting confidentiality
- does not deter people from HIV testing
- supports equitable allocation of resources and projection of resources needed in future for care and prevention
- enhances ability to target and evaluate prevention efforts
- more complicated than name reporting to administer
- more difficulty obtaining compliance with system, affecting completeness and accuracy of data (with training timely, reliable data can be provided)
- more difficult to provide follow-up and links to treatment and services

Pros

The greatest benefit of a unique identifier system is that such a system maintains the confidentiality of HIV-infected persons and strengthens our capacity to protect private information. Each time a unique identifier is generated, whether by a health care provider or public health official, there is a reminder that this is valuable and private information which needs to be protected by an individual code.

Unlike a name reporting system, a unique identifier system does not undermine the public health goals of early testing and medical intervention. The knowledge that their names will not be reported to an HIV registry can help alleviate people's concern about testing, and ultimately result in more people seeking HIV testing. If more people are tested, there is more comprehensive, representative and accurate data on which to base decisions about resource allocation, and more reliable indications of how well prevention efforts are working. As one expert notes, "Because it lowers the risk of testing avoidance, unique identifier-based reporting is, arguably, a more effective data collection tool than mandatory name reporting will ever be."[16]

Depending on how they are structured, unique identifier reporting systems can prevent duplication of reports even more effectively than name reporting. For example, it is quite possible that there could be two people with the same name in a reporting area. Under a name-based system, this could appear to be a duplicative report, and one person's record might be deleted. If there were a unique identifier system using birth dates or part of the Social Security number, this would most likely be avoided.

While unique identifier reporting systems are relatively untried, the investment to date in such systems demonstrates that they can be developed in a way which is easy to administer. The most advanced unique identifier system in use in the United States is in Maryland (France and Australia also use unique identifier systems).

---

[16] A. Forbes, "Naming Names," *AIDS Policy and Law*, May, 1996.

In creating its unique identifier reporting system, Maryland specified that the code needed:

- to be simple to generate (taking not more than 90 seconds, not necessitating a computer, and not dependent on subjective determinations by staff)
- to have immutable data elements
- to be generated from factual information provided by the client
- to have a duplication rate less than or equal to two percent (less than two chances in 100 that a person could be assigned two different codes)
- to be difficult to decipher
- not to depend on an individual's ability to recall and accurately report a previously assigned code[17]

In only three years of reporting under a unique identifier system, Maryland has achieved 96.6 percent completeness in reporting by state-funded testing sites. While private testing sites in the state have a lower completeness rate, this rate has been improving steadily, and can be expected to get even better as health care providers become more familiar with the system. Maryland's example, among others, suggests that with the proper investment and appropriate training of health care providers and public health officials, unique identifier reporting systems can work as a method of HIV surveillance.

Cons

Unique identifier reporting systems are more expensive and will take more time to successfully implement than name reporting systems. Resources must be invested initially to determine the type of unique identifier which will be used, and to establish procedures for generating and reporting unique identifier codes. Unique identifier systems are inherently more complex than name reporting systems, and thus more costly to operate.

Compared to name reporting, we have relatively little experience with creating and administering unique identifier reporting systems. It may be difficult for public health epidemiologists, who are accustomed to name reporting, to adjust to unique identifier reporting.

Collecting the information necessary and generating unique identifier codes will add time and costs to already overburdened health care and public health systems. Until health care providers and public health officials become familiar and comfortable with a unique identifier system, there will be delays in reporting.

Because of unfamiliarity with the process and increased administrative burdens, unique identifier reporting systems can have problems with health care provider compliance. Lack of compliance results in a lack of completeness of the information collected. This has been an issue in Texas, where officials estimate that up to 70 percent of reports received are incomplete.[18]

---

[17] A. Forbes, "A Brief Overview of the Unique Identifier System Used by the Maryland Department of Health and Mental Hygiene for HIV and CD Reporting," July, 1997.

[18] AIDS Project Los Angeles, *HIV Surveillance: Proposals for the New Era of the HIV Epidemic*, Summer 1997.

In using codes rather than names, unique identifier systems make it more difficult, if not impossible, to follow up with individuals for treatment and services. Should an expansion of Medicaid be created, for example, unique identifier reporting would not enable public health officials to locate HIV positive individuals to tell them of this change and advise them about their eligibility for the program.

Conclusion

Under current conditions, unique identifier reporting will better achieve the public health goals of HIV surveillance than will name reporting. An investment in unique identifier reporting can provide a comprehensive picture of the epidemic, while also protecting confidentiality and not discouraging people from seeking HIV testing. Unique identifier reporting can provide data which can help us allocate limited resources, target and evaluate prevention efforts, educate the public about the epidemic, and project where the epidemic is going.

At the present time, we believe that the negative aspects of name reporting outweigh its potential benefits, and therefore oppose making this approach mandatory. Name reporting deters people from HIV testing, undermining an important public health objective. Currently, our privacy protection laws are not strong enough to deter breaches of confidentiality. Name reporting is not currently accompanied by guaranteed access to care and treatment. If we were to enact a strong federal confidentiality law which did not preempt stronger state laws, and to assure access to care and treatment for all HIV infected people, a reevaluation of the potential benefits of a name reporting system would be appropriate.

In considering moving from AIDS to HIV surveillance, the CDC must have a dialogue with consumers and advocates. The CDC must also work with the Health Resources and Services Administration, the Health Care Financing Administration, and the Department of Justice to address thoughtfully issues of access to care, reallocation of resources and creation of strong legal protections for privacy.

Now is the time for the federal government to provide the resources to support states which want to create unique identifier reporting systems. This does not mean creating special rights or a special system solely for HIV. It means investing in establishing a system which can meet the current needs of the HIV epidemic while expanding the tools available for effectively gathering surveillance data to meet a broad range of public health objectives in the future. **Therefore, AIDS Action supports the establishment of HIV surveillance using unique identifier reporting.**

Table 1
HIV Reporting Requirements in the 50 States, District of Columbia, Puerto Rico, and the U.S. Virgin Islands (alphabetically)

STATE	Reporting Type	STATE	Reporting Type	STATE	Reporting Type
Alabama	Name	Louisiana	Name	Oklahoma	Name
Alaska	Not Required	Maine	Anonymous	Oregon****	Anonymous
Arizona	Name	Maryland**	Unique Identifier	Pennsylvania	Not Required
Arkansas	Name	Massachusetts	Not Required	Puerto Rico	Not Required
California	Not Required	Michigan	Name	Rhode Island	Anonymous
Colorado	Name	Minnesota	Name	South Carolina	Name
Connecticut*	Not Required	Mississippi	Name	South Dakota	Name
Delaware	Not Required	Missouri	Name	Tennessee	Name
District of Col.	Not Required	Montana	Anonymous	Texas*	Unique Identifier
Florida	Name	Nebraska	Name	Utah	Name
Georgia	Anonymous	Nevada	Name	Vermont	Not Required
Hawaii	Not Required	New Hampshire	Anonymous	Virginia	Name
Idaho	Name	New Jersey	Name	Virgin Islands	Anonymous
Illinois	Anonymous	New Mexico***	Name	Washington**	Not Required
Indiana	Name	New York	Not Required	West Virginia	Name
Iowa	Anonymous	North Carolina	Name	Wisconsin	Name
Kansas	Anonymous	North Dakota	Name	Wyoming	Name
Kentucky	Anonymous	Ohio	Name		

* Connecticut and Texas require name reporting of HIV infection in children under 13 years old.
** Maryland and Washington require name reporting of symptomatic HIV infection.
*** New Mexico is in the process of implementing HIV name reporting.
**** Oregon requires name reporting of HIV infection in children under 6 years old.

Table 1A
HIV Reporting Requirements in the 50 States, District of Columbia, Puerto Rico, and the U.S. Virgin Islands (by type of reporting)

NAME REPORTING	NAME REPORTING (cont'd.)	UNIQUE IDENTIFIER REPORTING	ANONYMOUS REPORTING	REPORTING NOT REQUIRED
Alabama	New Jersey	Maryland**	Georgia	Alaska
Arizona	New Mexico*	Texas***	Illinois	California
Arkansas	North Carolina		Iowa	Connecticut***
Colorado	North Dakota		Kansas	Delaware
Florida	Ohio		Kentucky	District of Col.
Idaho	Oklahoma		Maine	Hawaii
Indiana	South Carolina		Montana	Massachusetts
Louisiana	South Dakota		New Hampshire	New York
Michigan	Tennessee		Oregon****	Pennsylvania
Minnesota	Utah		Rhode Island	Puerto Rico
Mississippi	Virginia		Virgin Islands	Vermont
Missouri	West Virginia			Washington**
Nebraska	Wisconsin			
Nevada	Wyoming			

* New Mexico is in the process of implementing HIV name reporting.
** Maryland and Washington require name reporting of symptomatic HIV infection.
*** Texas and Connecticut require name reporting of HIV infection in children under 13 years old.
**** Oregon requires name reporting of HIV infection in children under 6 years old.

The New England Journal of Medicine

Established in 1812 as THE NEW ENGLAND JOURNAL OF MEDICINE AND SURGERY

VOLUME 337 OCTOBER 16, 1997 NUMBER 16

THE NEW ENGLAND JOURNAL OF MEDICINE (ISSN 0028-4793) is published weekly from editorial offices at 10 Shattuck Street, Boston, MA 02115-6094. Subscription price: $119.00 per year. Periodicals postage paid at Boston and at additional mailing offices. POSTMASTER: Send address changes to P.O. Box 803, Waltham, MA 02254-0803.

Sounding Board

National HIV Case Reporting for the United States

A Defining Moment in the History of the Epidemic

REPORTING of patients with AIDS by name (AIDS surveillance) has until now formed the cornerstone of the nation's efforts to monitor and characterize the epidemic of human immunodeficiency virus (HIV) infection. AIDS surveillance tracked the growth of the disease from a small number of cases in a few large cities on the East and West coasts to a national epidemic and a leading cause of death among persons 25 to 44 years of age.[1] AIDS surveillance focuses on the most advanced stage of HIV disease, which — in the absence of effective treatment — develops on average 10 years after initial infection. Consequently, the AIDS reporting system provides a snapshot of a decade-old epidemic. Innovative antiretroviral therapies are now further delaying the progression of HIV disease, thus significantly affecting trends in AIDS reporting. The compelling need for accurate monitoring of HIV infection and for effective medical and public health interventions mandates a fundamental reevaluation of AIDS surveillance. In this paper, we present the argument for a national system of HIV case reporting in the United States.

AIDS reporting can be understood only by examining its unique history.[2] In 1981, shortly after clusters of cases of unusual pneumonia and rare cancer were reported among gay men, the Centers for Disease Control (CDC) determined that the syndrome's likely cause was a transmissible agent spread by the same routes as hepatitis B.[3,4] Even before the virus was discovered and an antibody test was approved, however, states instituted reporting of AIDS cases with names, a measure that generated little public or political controversy.[5] Not until late 1983 did researchers identify the causative agent of AIDS, then called the human T-cell lymphotropic virus type III (HTLV-III) in the United States and lymphadenopathy-associated virus (LAV) in France.[6,7] The Food and Drug Administration did not license the antibody test until 1985, and then only to screen the nation's blood supply.[8] Thus, AIDS surveillance can be explained historically: it was predicated on epidemiologic investigations of an end-stage syndrome and implemented before antibody testing for the causative agent was available.

AIDS surveillance was, and still is, broadly accepted among the community of persons living with HIV infection and AIDS. The relatively short period of patients' survival, as well as the need for health and human services, was thought to offset the social risks of surveillance. In contrast, HIV case reporting has generated bitter political controversy and impassioned community resistance. The first requirement of HIV reporting, in Colorado, and the early public health proposals for HIV surveillance in the mid-1980s ignited a firestorm of community protest.[5] Civil libertarians and gay organizations opposed HIV case reporting because they did not trust the government to maintain sensitive registries and they were concerned about political retribution, potential invasions of personal privacy, and discrimination in employment, housing, and insurance.

The United States has recently entered an era of ever more sophisticated advances in the knowledge and treatment of HIV disease. Instead of being a latent infection, as previously believed, HIV infection is now known to produce high rates of viral replication and death of CD4+ cells soon after transmission.[9] Recent research suggests that a treatment regimen of HIV reverse-transcriptase inhibitors and protease inhibitors reduces mortality and delays progression of disease.[10-13] Persons receiving such a regimen have been found to have lower levels of circulating virus, suggesting that treatment not only benefits the patient but may also reduce the risk of transmission. Antiretroviral therapy has been shown to decrease perinatal transmission of HIV markedly.[14,15] Although the long-term benefits are unknown and much research remains to determine the role of treatment in reducing infectiousness, delaying or preventing clinical manifestations of disease, and developing resistant strains of HIV, innovative therapies are already dramatically affecting the AIDS epidemic.

In 1996, the incidence of both deaths and opportunistic illnesses due to AIDS declined for the first time in the history of the epidemic.[16] Deaths due to AIDS decreased 23 percent (to approximately 39,000), and the decline was even greater for certain populations, such as homosexual and bisexual men (30 percent). In the same year, approximately 56,730 cases of AIDS were diagnosed, representing a 6 percent decline in incidence from the previous year. As more persons infected with HIV are treated, the effect on these trends should become even more striking. A CDC survey of HIV-infected persons without AIDS-defining conditions who were receiving clinical care from 1996 through early 1997 found that only 5 percent of the 2932 subjects had had an HIV-protease inhibitor prescribed (CDC: unpublished data). Revised treatment guidelines based on the viral burden and numbers of CD4+ lymphocytes include the recommendation that HIV-infected persons be treated long before AIDS or the symptoms of HIV disease develop.[13]

We are at a defining moment in the epidemic of

HIV infection and AIDS. With therapy that delays the progression to AIDS-related illnesses and death, HIV infection or AIDS is becoming a complex clinical disease that does not lend itself to monitoring based only on end-stage illness. Unless we revise our surveillance system, health authorities will not have reliable information about the prevalence, incidence, and future directions of HIV infection, the kinds of behavior that currently increase the risk of HIV transmission, or the heightened impact on specific subpopulations, such as racial and ethnic minorities and women. To correct these deficits, we propose that all states require HIV case reporting.

CURRENT STATUS OF HIV AND AIDS SURVEILLANCE

Since 1981, national, state, and local monitoring of the scope and impact of the epidemic has been based on AIDS surveillance. Every state has a statute or regulation requiring laboratories and physicians to report the names of persons with newly diagnosed AIDS to health departments.[17] To provide complete, timely, and accurate data, case reports follow uniform standards. The information reported includes demographic data, the name of the physician or laboratory making the diagnosis, the patient's risk history, a laboratory analysis, the patient's clinical status, and any referrals for treatment or services.[18] State health departments, in turn, forward case reports to the CDC using a soundex code, wherein information that identifies patients is deleted and the data are encrypted for aggregation at the national level. From 1981 through June 30, 1997, state and local health departments reported 612,078 cases of AIDS to the CDC.[19]

HIV-surveillance reports are recorded locally and forwarded to the CDC by the same system used for AIDS cases.[20] Twenty-six states require that HIV case surveillance of adults and adolescents who test positive for HIV antibody remain confidential.[21] In addition, Florida and New Mexico plan to begin HIV surveillance in late 1997 or early 1998. Three other states conduct HIV surveillance for pediatric cases only.[22] The 26 states currently requiring HIV case surveillance for adults and adolescents, however, account for just 24 percent of the AIDS cases reported to the CDC through 1996.[19] Of the 10 states with the highest rates of reported AIDS cases in 1996, only New Jersey and Louisiana conduct HIV case surveillance.

Thus, AIDS reporting remains the primary focus of national surveillance. Some legislators and members of the public question whether concern about civil rights and privacy has taken precedence over the health of the community,[23,24] and whether HIV infection and AIDS have been treated differently from other infectious diseases.[25-27]

JUSTIFICATIONS FOR NATIONAL HIV CASE REPORTING IN THE UNITED STATES

We believe that multiple methods of surveillance for HIV infection and AIDS (e.g., reporting, in-depth interviews, medical-record reviews, unlinked seroprevalence surveys, and sampling of representative populations) covering the full spectrum of the disease would promote the public's health.[28-31] In particular, a national system of confidential HIV case reporting would improve our understanding of the epidemic, help to target prevention and public health services, provide a link to health and social services, and result in better allocation of resources.[32-35]

MONITORING THE EPIDEMIC

A national HIV-surveillance system would markedly improve epidemiologic assessments of the epidemic and help to answer vital public health questions: How many people in the United States are infected with HIV? How many of these infections are newly acquired and diagnosed? How were these newly diagnosed infections contracted? Are persons with HIV infection receiving appropriate medical and social services? How effective is treatment, and what strains of HIV are becoming resistant to treatment? Which communities have the highest rates of new infections?

The national HIV-surveillance system we propose would yield relevant data about various aspects of the epidemic. First, the system would monitor the methods by which HIV infection is acquired and transmitted by measuring the precursors to infection, such as risky behavior and modes of transmission (e.g., sexual contact, perinatal transmission, use of shared needles, and accidental needle sticks). Second, data collection on recent HIV infections would offer a window on the emerging trends of the epidemic. Third, monitoring HIV-related deaths would improve understanding of the number of persons with HIV infection and the characteristics of those for whom treatment fails. Finally, a national HIV-surveillance system would collect laboratory markers of disease severity (e.g., HIV RNA and CD4+ values) and monitor preventable opportunistic illnesses, thus enabling health authorities to characterize the natural history of HIV disease and to evaluate the access to and efficacy of medical treatment.

TARGETING PREVENTION AND PUBLIC HEALTH SERVICES

An improved monitoring system would help target and evaluate effective prevention services, including population-based testing, counseling, and education. By directing scarce resources to geographic areas and subpopulations with the greatest needs, health authorities could most efficiently reduce HIV transmission. Research suggests that targeted servic-

es to prevent HIV infection are effective in both averting infections in high-risk populations and reducing costs.[36] Enhanced surveillance is useful in community planning for the prevention of HIV infection, implementing public health strategies, and evaluating their efficacy. For example, a recent analysis by the CDC found that, in 1993, states conducting HIV surveillance were able to identify 49 percent of the children born to infected mothers, as compared with 5 percent in states that reported AIDS alone.[37] These types of data could enable states to develop more effective strategies (e.g., testing, counseling, and treatment) to reduce perinatal transmission and provide services for HIV-infected mothers and children.

LINKING PERSONS WITH HIV INFECTION TO HEALTH EDUCATION, TREATMENT, AND PARTNER-NOTIFICATION SERVICES

HIV surveillance benefits people with HIV infection or AIDS by providing them with a connection to health education, treatment, and support services for voluntary notification of partners.[38] Where HIV infection is reportable, public health authorities have greater ability to ensure timely referrals for health and social services. Studies suggest that client-centered counseling and health education reduce the risk of HIV transmission.[39,40] Persons with HIV infection or AIDS who receive early treatment are more likely to live longer and to lead higher-quality lives.[41,42] Moreover, case reporting makes it easier to notify the sexual and needle-sharing partners of persons infected with HIV and to refer them for treatment.[43,44]

Improved surveillance will not, of course, ensure that persons with HIV infection receive services. There are many barriers to health and social services, notably those related to cost, geographic accessibility, and culture. Public health agencies have long provided government-funded counseling, treatment, and partner-notification services for persons with sexually transmitted diseases. HIV surveillance would receive more enthusiastic community support if it, too, were explicitly linked to health and human services.

ALLOCATING FUNDING

Historically, the allocation of resources has been based on AIDS-surveillance data, particularly for programs falling under the purview of the Ryan White Care Act and other federally sponsored efforts. Data on AIDS were used because they were universally available and provided a standardized and representative accounting of the number of persons with severe HIV disease.

Health care planning based on trends in HIV infection instead of AIDS, however, would provide a more accurate assessment of the distribution of the infected population, the number of people gaining access to treatment, and the kinds of providers offering treatment. Accurate estimates of the current status and future directions of HIV infection could mobilize political opinion in favor of greater and more enduring funding for surveillance, prevention, research, and treatment. There is a danger that the trend toward decreasing numbers of AIDS cases may be mistakenly viewed as reflecting a similar decline in HIV infection. Similarly, political efforts to protect the health of women, children, and racial minorities would be best served by surveillance that reveals the nature and extent of HIV infection in those groups. As compared with AIDS, for instance, a higher proportion of the cases of HIV infection reported in 1996 occurred among women (AIDS, 20 percent; HIV infection, 30 percent), African Americans (AIDS, 48 percent; HIV infection, 55 percent), and young people 13 to 24 years of age (AIDS, 4 percent; HIV infection, 17 percent) (unpublished data).

Eligibility for Medicaid is currently tied to the CDC definition of AIDS. This system creates hardships for people with HIV infection and for the larger community. To become eligible for Medicaid, poor people with HIV infection must wait until they either become seriously immunologically impaired or acquire opportunistic infections. Since combination therapies are prohibitively expensive (averaging $12,000 to $18,000 annually),[45] poor people may not have access to treatment. As a result, untreated persons with HIV infection may have high levels of circulating virus rendering them more infectious, less likely to live independently and maintain their employment, and more likely to require costly hospital care.[46] Given the changing pattern of the epidemic and the markedly improved clinical outcomes, rational decisions about the allocation of resources and eligibility for government benefits cannot continue to be based on the CDC's current definition of AIDS.[47]

THE BEHAVIORAL AND SOCIAL IMPACT OF NAMED HIV REPORTING

The most telling objections to HIV surveillance are behavioral and social and relate to issues of voluntary testing, privacy, and discrimination.[48] Public health authorities and community representatives share a single core concern about HIV case reporting: that it might deter people from being tested and seeking care.[49] Persons at risk for HIV infection are advised to undergo testing to receive needed counseling and treatment.[40] If such persons are required by law to report their names to health officials, will they decline to be tested or delay seeing a physician?

Although definitive studies have yet to be published, preliminary data indicate that HIV case reporting does not provide a distinct disincentive to testing. However, a survey of 2387 persons at risk for

HIV infection showed that only 31 percent of the respondents in states where HIV infection is reported were aware of case reporting. Since most respondents did not know the legal requirements of their states, they were unlikely to have altered their behavior because of them. Respondents also said they were more likely to be tested for HIV if the testing was anonymous.[50] Additional studies emphasize the importance of alternative test sites in encouraging voluntary testing.[51-55] More work is necessary to ensure community acceptance of case reporting.

ANONYMOUS-TESTING OPTIONS

We recommend alternative test sites (offering anonymous testing) as an important adjunct to a national system of HIV case reporting. Currently, 10 states do not offer alternative test sites (Alabama, Idaho, Mississippi, Nevada, North Carolina, North Dakota, South Carolina, South Dakota, Tennessee, and Wyoming). The potential health consequences of failing to offer anonymous HIV testing include delays in testing and care, increased blood donations by people at risk for HIV who seek anonymous testing, and less accurate HIV surveillance because of false information given at confidential testing sites.[56] Persons who purchase home testing kits possess the means to be tested anonymously. Considerations of equity, as well as public health, militate in favor of free public access to anonymous HIV testing in all jurisdictions.

THE NEED FOR PRIVACY OF HEALTH INFORMATION

Strict privacy and security of HIV data are necessary to ensure the success of a national system of HIV case reporting. Persons with HIV or AIDS have potent reasons for desiring privacy. Not only is HIV infection a serious and costly disease, but its disclosure may also expose intimate information about a person's sexual or drug-using behavior. In addition, physicians and patients may perceive the reporting of test results, demographic information, and risky behavior to a government agency as a breach of trust.[57] Unauthorized disclosures, moreover, may embarrass the patient and result in discrimination in housing, employment, and health care.

Health departments have a strong history of maintaining the confidentiality of reported information, but community anxieties have been heightened by well-publicized invasions of privacy. In Florida, for instance, a health official, without authorization, publicly revealed names from an HIV registry.[58] The judiciary has sometimes ordered HIV data to be disclosed for the purposes of litigation.[59] Moreover, state legislatures may abuse HIV surveillance for political purposes. For example, Illinois enacted but never implemented legislation requiring the health department to identify HIV-positive health care workers by cross-matching the state AIDS registry against health care–licensure records.[60]

The most stringent legal protections of privacy apply to government-held health information (including records maintained by state and local health departments) and particularly to HIV data.[61,62] The Supreme Court requires that states provide reasonable levels of privacy and security for reported health data.[63] Virtually all states protect the privacy of government-held data by statute. In addition, most states have enacted HIV-specific privacy legislation that imposes stricter standards for HIV information.[64] Furthermore, the federal government offers an assurance of confidentiality for surveillance information about HIV infection and AIDS, prohibiting the use of personally identifiable data for any purpose other than that for which it was provided (unless the supplier of the information has consented to an alternative use).[65] The Americans with Disabilities Act of 1990 also proscribes discrimination in employment, public accommodations, and public services for persons with HIV infection or AIDS.[66]

Privacy problems with HIV data already exist. The names of persons with HIV infection have already been entered into other data bases, such as those of Medicaid, drug-assistance registries, and public health registries for other reportable conditions. Sensitive HIV data are also collected, stored, and widely used by insurers, managed-care organizations, and researchers.

UNIQUE IDENTIFIERS: AN ALTERNATIVE TO NAMED SURVEILLANCE

A key privacy principle holds that public health information must be the narrowest in content, the least identifiable and sensitive, and disclosed to the fewest possible to achieve the public health purpose.[62] Consequently, HIV surveillance that could be conducted as effectively, or more so, without revealing the patient's identity would be preferred to reporting by name. Methods such as computer encryption and the generation of unique identifiers that do not include the patient's name permit the collection and storage of data in virtually unidentifiable form. At present, though, these methods are not routinely used, because unique identifiers do not yet provide high-quality, unduplicated HIV data at a reasonable cost.

Two states — Maryland and Texas — currently conduct HIV surveillance using unique identifiers without names. These identifiers consist of the last four digits of the Social Security number, birth date, sex, and race. Both states have found that their data contain a substantial number of incomplete and difficult-to-match records. In contrast, countries such as Australia and the United Kingdom routinely use coded, anonymous HIV-surveillance systems, but their lower rates of HIV infection and the structures of their

health care systems limit the application of their methods.[67-69]

Anonymous reporting complicates the task of obtaining complex data about risky behavior and natural history — the type of information that is available from interviews with physicians and patients and from reviews of medical records, and that is currently accessed through the patient's name.

THE FUTURE OF HIV SURVEILLANCE

Reporting requirements involved an enduring conflict of values between individual rights to privacy and the collective good of society.[57] Perhaps the initial resistance to HIV case reporting was warranted by the sensitivity to a new and frightening disease that placed a disproportionate burden on disfavored populations. Baffling science for years, the disease left people who had HIV infection and their partners without the benefit of effective treatment. Given the need for privacy and the near absence of effective interventions, individual rights were thought to outweigh the benefits of HIV surveillance.

With advances in science, medicine, epidemiology, and law, however, we are now at a very different point in the history of the epidemic. Collective justifications for a national system of HIV case reporting are compelling. HIV reporting would improve our understanding of the epidemiology of the epidemic; prevent infections by targeting scarce resources for testing, counseling, education, and partner notification; benefit persons with HIV or AIDS and their partners by providing a link to medical treatment and other human services; and promote more equitable allocation of government funding.

Our recommendation for a national system of HIV case reporting — emanating, as it does, from the public health, advocacy, and academic communities — is a positive example of partnerships between public health officials and communities. This collaboration will lead to an HIV-reporting system that is both scientifically sound and protective of personal privacy.

LAWRENCE O. GOSTIN, J.D.
Georgetown University Law Center
Washington, DC 20001

JOHN W. WARD, M.D.
Centers for Disease Control and Prevention
Atlanta, GA 30333

A. CORNELIUS BAKER
National Association of People with AIDS
Washington, DC 20005

This article was based on a national consultation on HIV surveillance conducted by the CDC and the Council of State and Territorial Epidemiologists held at the Carter Presidential Center in Atlanta on May 21–22, 1997.

REFERENCES

1. Update: trends in AIDS incidence, deaths, and prevalence — United States, 1996. MMWR Morb Mortal Wkly Rep 1997;46:165-73.
2. Institute of Medicine. Confronting AIDS: directions for public health, health care, and research. Washington, D.C.: National Academy Press, 1986.
3. Masur H, Michelis MA, Greene JB, et al. An outbreak of community-acquired *Pneumocystis carinii* pneumonia: initial manifestation of cellular immune dysfunction. N Engl J Med 1981;305:1431-8.
4. Francis DP, Curran JW, Essex M. Epidemic acquired immune deficiency syndrome: epidemiologic evidence for a transmissible agent. J Natl Cancer Inst 1983;71:1-4.
5. Bayer R. Private acts, social consequences: AIDS and the politics of public health. New York: Free Press, 1989.
6. Baare-Sinoussi F, Chermann JC, Rey F, et al. Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS). Science 1983;220:868-71.
7. Gallo RC, Salahuddin SZ, Popovic M, et al. Frequent detection and isolation of cytopathic retroviruses (HTLV-III) from patients with AIDS and at risk for AIDS. Science 1984;224:500-3.
8. Provisional Public Health Service inter-agency recommendations for screening donated blood and plasma for antibody to the virus causing acquired immunodeficiency syndrome. MMWR Morb Mortal Wkly Rep 1985;34:1-5.
9. Perelson AS, Neumann AU, Markowitz M, Leonard JM, Ho DD. HIV-1 dynamics in vivo: virion clearance rate, infected cell life-span, and viral generation time. Science 1996;271:1582-6.
10. Hammer SM, Katzenstein DA, Hughes MD, et al. A trial comparing nucleoside monotherapy with combination therapy in HIV-infected adults with CD4 cell counts between 200 to 500 per cubic millimeter. N Engl J Med 1996;335:1081-90.
11. Saravolatz LD, Winslow DL, Collins G, et al. Zidovudine alone or in combination with didanosine or zalcitabine in HIV-infected patients with the acquired immunodeficiency syndrome or fewer than 200 CD4 cells per cubic millimeter. N Engl J Med 1996;335:1099-106.
12. Collier AC, Coombs RW, Schoenfeld DA, et al. Treatment of human immunodeficiency virus infection with saquinavir, zidovudine, and zalcitabine. N Engl J Med 1996;334:1011-7.
13. Carpenter CC, Fischl MA, Hammer SM, et al. Antiretroviral therapy for HIV infection in 1997: updated recommendations of the International AIDS Society–USA panel. JAMA 1997;277:1962-9.
14. Peckham C, Gibb D. Mother-to-child transmission of the human immunodeficiency virus. N Engl J Med 1995;333:298-302.
15. Fiscus SA, Adimora AA, Schoenbach VJ, et al. Perinatal HIV infection and the effect of zidovudine therapy on transmission in rural and urban counties. JAMA 1996;275:1483-8.
16. Update: trends in AIDS incidence — United States, 1996. MMWR Morb Mortal Wkly Rep 1997;46:861-7.
17. Update: public health surveillance for HIV infection — United States, 1989 and 1990. MMWR Morb Mortal Wkly Rep 1990;39:853, 859-61.
18. Adult HIV/AIDS confidential case report. CDC50.42A. Bethesda, Md.: Department of Health and Human Services, 1993.
19. Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997. Vol. 9. No. 1.
20. HIV infection reporting — United States. MMWR Morb Mortal Wkly Rep 1989;38:496-9.
21. Centers for Disease Control and Prevention. Alabama, Arizona, Arkansas, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, Wyoming. HIV/AIDS Surveillance Report, 1996. Vol. 8. No. 2. 29.
22. *Idem.* Connecticut and Texas require reporting for pediatric cases of children less than 13 years old: Oregon requires reporting for pediatric cases of children less than 6 years of age. HIV/AIDS Surveillance Report, 1996. Vol. 8. No. 2.
23. Burr C. The AIDS exception: privacy vs. public health. Atlantic Monthly. June 1996:57-67.
24. Richardson L. Progress on AIDS treatments brings movement for less secrecy. New York Times. August 21, 1997:A1.
25. Bayer R. Public health policy and the AIDS epidemic: an end to HIV exceptionalism? N Engl J Med 1991;324:1500-4.
26. Angell M. A dual approach to the AIDS epidemic. N Engl J Med 1991;324:1498-500.
27. Steinbrook R. Battling HIV on many fronts. N Engl J Med 1997;337:779-80.
28. Sweeney P, Fleming PL, Ward JW. Monitoring current HIV transmis-

sion to promote prevention: supplementing AIDS surveillance. AIDS 1995;9:645-7.
29. Farizo KM, Buehler JW, Chamberland ME, et al. Spectrum of disease in persons with human immunodeficiency virus infection in the United States. JAMA 1992;267:1798-805.
30. Buehler JW, Diaz T, Hersh BS, Chu SY. The supplement to HIV-AIDS surveillance project: an approach for monitoring HIV risk behaviors. Public Health Rep 1996;111:Suppl 1:133-7.
31. McQuillan GM, Khare M, Karon JM, Schable CA, Vlahov D. Update on the seroepidemiology of human immunodeficiency virus in the United States household population: NHANES III, 1988-1994. J Acquir Immune Defic Syndr Hum Retrovir 1997;14:355-60.
32. CDC Advisory Committee on the Prevention of HIV Infection. External review of CDC's HIV prevention strategies. Atlanta: Centers for Disease Control and Prevention, 1994.
33. Strategic plan for preventing human immunodeficiency virus (HIV) infection. Atlanta: Centers for Disease Control and Prevention, 1992.
34. Position statement: confidential reporting of HIV infection. Atlanta: Council of State and Territorial Epidemiologists, 1997.
35. Ward JW, Fleming PL, Buehler JW. Annotation: what will be the role of HIV infection reporting? Am J Public Health 1994;84:1888-9.
36. Kahn JG. The cost-effectiveness of HIV prevention targeting: how much more bang for the buck? Am J Public Health 1996;86:1709-12.
37. Wortley PM, Fleming PL, Lindegren M-L, Sweeney PA, Davis S. Using HIV/AIDS surveillance to monitor public health efforts to reduce perinatal transmission of HIV. J Acquir Immun Defic Syndr Hum Retrovir 1996;11:205-6.
38. Hoffman RE, Spencer NE, Miller LA. Comparison of partner notification at anonymous and confidential HIV test sites in Colorado. J Acquir Immune Defic Syndr Hum Retrovir 1995;8:406-10.
39. Kamb ML, Rhodes F, Bolan G, et al. Does HIV/STD counseling work? Results from a randomized controlled trial (Project Respect). Presented at the Fourth Conference on Retroviruses and Opportunistic Infections, Washington, D.C., January 22–26, 1997. abstract.
40. HIV counseling, testing, and referral standards and guidelines. Atlanta: Centers for Disease Control and Prevention, 1994.
41. Report of the NIH Panel to Define Principles of Therapy of HIV Infection and guidelines for the use of antiretroviral agents in HIV-infected adults. Washington, D.C.: Department of Health and Human Services, 1997.
42. Staszewski S, Hill AM, Bartlett J, et al. Reductions in HIV-1 disease progression for zidovudine/lamivudine relative to control treatments: a meta-analysis of controlled trials. AIDS 1997;11:477-83.
43. Bayer R, Toomey KE. HIV prevention and the two faces of partner notification. Am J Public Health 1992;82:1158-64.
44. Guide to public health practice: HIV partner notification strategies. Washington, D.C.: Association of State and Territorial Health Officials, 1988.
45. HIV/AIDS and Medicaid: standards of care for new therapies. Medicaid Pharm Bull 1996;10:1-6.
46. Pear R. Medicaid may be extended to early treatment of AIDS. New York Times, June 1, 1997:20.
47. Francis DP, Singleton JA. Reporting of HIV-1 infection through the provision of essential services. J Acquir Immune Defic Syndr 1993;6:285-6.
48. Forbes A. Naming names — mandatory name-based HIV reporting: impact and alternatives. AIDS Policy & Law. May 1996:1-4.
49. Should HIV test results be reportable? A discussion of the key policy questions. Washington, D.C.: AIDS Action Foundation, 1993.
50. Hecht FM, Colman S, Lehman JS, et al. Named reporting of HIV: attitudes and knowledge of those at risk. J Gen Intern Med 1997;12:Suppl 1:108. abstract.
51. Hirano D, Gellert GA, Fleming K, Boyd D, Englender SJ, Hawks H. Anonymous HIV testing: the impact of availability on demand in Arizona. Am J Public Health 1994;84:2008-10.
52. Kegeles SM, Catania JA, Coates TJ, Pollack LM, Lo B. Many people who seek anonymous HIV-antibody testing would avoid it under other circumstances. AIDS 1990;4:585-8.
53. Fehrs LJ, Fleming D, Foster LR, et al. Trial of anonymous versus confidential human immunodeficiency virus testing. Lancet 1988;2:379-82.
54. Meyer PA, Jones JL, Garrison CZ, Dowda H. Comparison of individuals receiving anonymous and confidential testing for HIV. South Med J 1994;87:344-7.
55. Phillips KA. The relationship of 1988 state HIV testing policies to previous and planned voluntary use of HIV testing. J Acquir Immune Defic Syndr 1994;7:403-9.
56. Statement of the National HIV Testing Action Coalition on the Necessity for Maintaining Anonymous HIV Testing Sites in All States. Washington, D.C.: HIV Testing Action Coalition, 1997.
57. Fox DM. From TB to AIDS: value conflicts in reporting disease. Hastings Cent Rep 1986;16(6):Suppl:11-6.
58. Landry S. AIDS list is out: state investigating breach. St. Petersburg Times, September 20, 1996:51.
59. Tarrant City Hospital District v. Huges, 734 SW2d 675 (Tex App 1987).
60. Public Act 87-763, sec. 693.40(3)(A) (1991).
61. Gostin LO. Health information privacy. Cornell Law Rev 1995;80: 451-528.
62. Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996;275:1921-7.
63. Whalen v. Roe, 429 U.S. 589 (1977).
64. Edgar H, Sandomire H. Medical privacy issues in the age of AIDS: legislative options. Am J Law Med 1990;16:155-222.
65. 42 U.S.C. 242m(d).
66. Gostin LO. The Americans with Disabilities Act and the U.S. health system. Health Aff (Millwood) 1992;11(3):248-57.
67. McDonald AM, Gertig DM, Crofts N, Kaldor JM. A national surveillance system for newly acquired HIV infection in Australia. Am J Public Health 1994;84:1923-8.
68. Smith E, Rix BA, Melbye M. Mandatory anonymous HIV surveillance in Denmark: the first results of a new system. Am J Public Health 1994; 84:1929-32.
69. Morris S, Gray A, Noone A, Wiseman M, Jathanna S. The costs and effectiveness of surveillance of communicable disease: a case study of HIV and AIDS in England and Wales. J Public Health Med 1996;18:415-22.